

**School of Psychology and Speech Pathology**

**Developing a bereavement risk  
assessment model for palliative care in  
Western Australia: An action research  
study**

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**This thesis is presented for the degree of  
Doctor of Philosophy  
of  
Curtin University**

**January 2016**



## **Declaration**

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC 00262), Approval Number # HR30/2013; Royal Perth Hospital Human Research Ethics Committee (EC2012/167); and South Metropolitan Health Service Human Research Ethics Committee (R/13/17).

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Date: 20 January 2016





## Abstract

**Introduction.** The death of a loved one is a normal and potentially intensely painful life event that the majority of people integrate into their lives. A minority of people, however, fail to move from the initial intense distress following a loss and are at risk of adverse mental and physical health outcomes, including having a greater risk of mortality. Bereavement support standards for palliative care advocate that caregivers of terminally ill patients receive support during the patient's illness and after the patient's death. The assessment of caregiver grief is necessary in order to provide appropriate support; however, research shows that present assessment relies on staff observation and intuition resulting in piecemeal support, which is both inappropriate and unsustainable.

**Aims.** The aim of the present study was to develop a bereavement risk assessment model, feasible for use in palliative care clinical practice. The model was based on a three-tiered public health approach aligning support with need. The model was intended to be congruent with bereavement support standards for specialist palliative care services. Standards advocate grief assessment is performed at intervals from the patient's admission to the service, to six months beyond the patient's death. Additional objectives of the study were: to identify existing grief measures in the literature for use in the model; to examine issues in relation to bereavement risk assessment in palliative care; and to identify the barriers to, and facilitators of, change in clinical practice.

**Method.** An action research approach was used in anticipation that collaboration with palliative care stakeholders would guide a clinically feasible bereavement risk assessment model for use in clinical practice. The study was conducted across five phases; 1) a scoping review of the literature to identify grief measures; 2) collaboration with a reference group of palliative care stakeholders to develop the model; 3) a pilot of the model at three different palliative care service models of care; 4) evaluation of the model with participating caregivers and health professionals and; 5) dissemination of findings to stakeholders. In response to findings in the first two phases, a brief grief measure was developed. The measure, comprised of 20 items with five Likert type frequency responses, included a broad range of risk factors for complicated or prolonged grief as identified in the literature.

Although action research was the overarching methodology, qualitative methods were used in the various phases of a study in order to achieve the study's goals. The study employed a reference group of palliative care stakeholders (n=9) in phase two; an advisory group of bereavement service providers and bereaved former caregivers (n=8) assisted in the development of the new grief measure in phase three; a brief pen and paper survey was administered to caregivers (n=19) who piloted the new measure in phase five; and focus group (n=4) and one-on-one semi-structured interview (n=1) methods were used in the evaluation (phase five). The data from the groups and interviews were analysed using an inductive thematic analysis approach.

**Results.** The scoping review of the literature identified 19 existing grief measures for potential use in a risk assessment model; however, the reference group of palliative care stakeholders found none to be suitable for use in the clinical setting. Themes from the reference group data included: systems of care/logistics of administering a measure; gatekeeping by staff; conflation between caregiver stress, burden and grief and also revealed a way forward. The themes highlighted a complexity of issues that will need to be managed if bereavement risk assessment is to become routine practice in future. Building on findings from phases one and two, a new brief grief measure was developed and piloted on caregivers in three palliative care services.

Evaluation regarding use of the new brief grief measure indicated the measure was largely acceptable to caregivers and to the palliative care staff who engaged in the assessment process; although similar barriers as found by the earlier reference group were also identified. Other themes emerging from the evaluation data included expectations in relation to the feasibility of assessment and the provision of support, the benefits of assessment and the potential utility of the measure in future, particularly in relation to documentation. The new measure was championed by a staff-member in one palliative care service where positive aspects to assessment were discovered; whereas, barriers hampered the assessment at another service.

**Conclusions.** Overall, the findings suggest that in spite of complexities in relation to the assessment of grief in palliative care, the new measure has a place in adding value to present assessments by streamlining the bereavement support decision-

making process. If modified, the measure also has potential for application as a staff administered assessment as well as for use in documentation such as advanced health planning and care of the dying pathways. The small numbers of caregivers participating in the study, make it impossible to draw any conclusions of the measure's worth as a grief instrument. The study has strength in that the health professionals and caregivers who participated in the various groups represented a broad range of services and health professional designations as a strong stakeholder group, and give a credible account of the issues that will need to be addressed if a bereavement risk assessment model is to become part of future practice. The scoping review is the first to provide a comprehensive overview of grief measures within the context of palliative care. Findings from the stakeholder group have highlighted the many issues relating to assessment underscoring a discrepancy between policy recommendations and clinical practice. As such, the study has laid the groundwork for developing a more robust bereavement risk assessment protocol in future. Future research must continue to focus on the many issues surrounding complicated grief responses, particularly in relation to the caregiving experience; the assessment of bereavement needs during caregiving; the types of support needed, and the ways in which support is provided to these caregivers. If assessment can be administered as sustainable practice in palliative care, and referral pathways to bereavement services can be established with community bereavement services, caregiver outcomes in terms of mental, physical health and mortality should improve markedly.



## Acknowledgements

“One man [sic] may hit the mark, another blunder; but heed not these distinctions. Only from the alliance of the one, working with and through the other, are great things born.” - Antoine de Sainte-Exupéry

This thesis could not have been completed without the assistance and support of so many people.

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invaluable and I am grateful for the insights you have provided. I am also glad that we have shared conference journeys and had some fun along the way. I will hold these special times in my heart forever. I have the utmost gratitude for the friendship and unwavering support of Geraldine who has been there through thick and thin, encouraging me when the going has been particularly tough. Sharing our undergraduate and PhD journey has created a special lifelong bond which I look forward to continuing in the coming years.

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Finally, I dedicate this to my family of origin, my parents, whose deep and overwhelming grief over the deaths of three sons has shaped my life from the moment I took my first breath. This thesis is dedicated to you ‘dead ones’ who are very much alive in my heart. If this work on bereavement support will make some small difference to just one person’s journey through grief then it will have been worth it.

## **List of Included Publications**

### **Chapter Four:**

Sealey, M., Breen, L.J., O'Connor, M., & Aoun, S. M. (2015). A scoping review of bereavement risk assessment measures: Implications for palliative care. *Palliative Medicine*, 29(7), 577-589. doi: 10.1177/0269216315576262

### **Chapter Five:**

Sealey, M., O'Connor, M., Aoun, S.M., & Breen, L.J.(2015). Exploring barriers to assessment of bereavement risk in palliative care: perspectives of key stakeholders. *BMC Palliative Care*, 14(49), 1-12. doi: 10.1186/s12904-015-0046-7

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## Statements of Contribution

### Statement of Contribution

To Whom It May Concern,

I, Margaret Anne Sealey, contributed to the conception and design of the research project, the collection and analysis of data obtained, the interpretation of the results, and drafted and revised the publication entitled "A scoping review of bereavement risk assessment measures: Implications for palliative care" published in *Palliative Medicine*, 29(7), 577-589. doi: 10.1177/0269216315576262

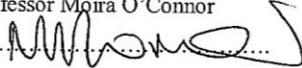
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I, as a co-author, endorse that this level of contribution by the candidate indicated above is appropriate.

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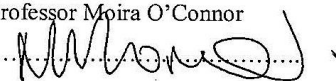
To Whom It May Concern,

I, Margaret Anne Sealey, contributed to the conception and design of the research project, the collection and analysis of data obtained, the interpretation of the results, and drafted and revised the publication entitled "Exploring barriers to assessment of bereavement risk in palliative care: perspectives of key stakeholders" published in *BMC Palliative Care*, 14(49), 1-12. doi: 10.1186/s12904-015-0046-7

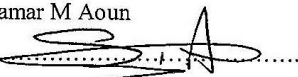


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Associate Professor Moira O'Connor

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Professor Samar M Aoun

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Dr Lauren J. Breen

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## **List of Additional Publications and Conference Presentations**

- Sealey, M., O'Connor, M., Breen, L.J., Aoun, S.M. (2015 September) Platform presentation, "Bereavement risk assessment in palliative care: The development of a brief grief measure to screen for carers who may be at risk of complex grief." 13<sup>th</sup> Australian Palliative Care Conference, Melbourne, Australia.
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- Sealey, M., O'Connor, M., Breen, L.J., Aoun, S.M. (2015 July) Platform presentation: "Developing a bereavement risk assessment model for palliative care in Western Australia: An action research study." Curtin University Denis Glencross Student Seminar, Perth, Australia.
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- Sealey, M., O'Connor, M., Breen, L.J., Aoun, S.M. (2014, September) Platform presentation "Bereavement risk assessment in palliative care" Western Australian Psycho-Oncology Group (WACOG) Research Symposium, Perth, Australia.

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- Sealey, M., O'Connor, M., Breen, L.J., Aoun, S.M. (2013 August) "Developing a bereavement risk assessment model for palliative care in Western Australia: An action research study." Curtin University Denis Glencross Student Seminar, Perth, Australia.
- Sealey, M., O'Connor, M., Breen, L.J., Aoun, S.M. (2012 October) Platform presentation "Thinking outside the box on bereavement risk assessment: A review of instruments and proposal of bereavement framework." Palliative Care WA State Conference, Perth, Australia.

## Abbreviations

AR.....	Action Research
CG.....	Complicated Grief
CGT.....	Complicated Grief Treatment
CSNAT.....	Carer Support Needs Assessment Tool
DPM.....	Dual Process Model
DSM.....	Diagnostic and Statistical Manual of Mental Health Disorders
GABA.....	Grief and Bereavement Assessment
GP.....	General Practitioner
HREC.....	Human Research Ethics Committee
ICD.....	International Classification of Diseases
IPT.....	Interpersonal Therapy
MDE.....	Major Depressive Episode
MDT.....	Multidisciplinary Team
NICE.....	National Institute for Clinical Excellence
NSAP.....	National Standards Assessment Program
PC.....	Palliative Care
PCBD.....	Persistent Complex Bereavement Disorder
PCIF.....	Participant Information and Consent Form
PCU.....	Palliative Care Unit
PGD.....	Prolonged Grief Disorder
PGD/CG.....	Prolonged Grief Disorder/Complicated Grief
PTSD.....	Posttraumatic Stress Disorder
TTMoB.....	Two-Track Model of Bereavement
UK.....	United Kingdom
USA.....	United States of America
WA.....	Western Australia
WHO.....	World Health Organization



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## CHAPTER ONE

### Introduction

*The system didn't work, and for a long time things were happening at home, and that's where a lot of the stress was. Because we just didn't know what to do. We didn't know where to go. We didn't know what was happening. We rang the hospital a few times, and it worked out that he'd sort of slipped through the system, and, I do believe that slipping through the system unfortunately happens a lot.* (Irena, bereaved former caregiver)

### Chapter Overview

Chapter one introduces this overarching study on developing a bereavement risk assessment model for palliative care, with a brief outline of issues related to grief and bereavement research. A detailed discussion of palliative care follows covering: a description of palliative care; how palliative care services are delivered; caregivers<sup>1</sup> who care for a patient in a palliative care service and the issues they face and; consequently why bereavement risk assessment is necessary in order to provide timely support for those potentially at risk of poor bereavement outcomes. The research questions posed at the commencement of the study are listed. The aims and the objectives of the study are detailed and the study's significance is discussed, along with a brief outline of my personal motivation for undertaking this research. The chapter concludes by summarising the structure of the thesis with an overview of each chapter's content.

### Grief and Bereavement

As Irena, the bereaved former caregiver, said in the opening sentences of this chapter, caring for a family member, loved one, or patient with a life-limiting illness is incredibly stressful. Many family caregivers are thrust into the support role unexpectedly with little or no training and are often uncertain of what to expect or where to seek information and support (Williams & McCorkle, 2011). As a result people are likely to fall through the gaps in the care system, between services and

---

<sup>1</sup> The terms caregiver or carer will be used throughout the thesis to refer to family members or friends caring for someone with a life-limiting illness.

between medical service providers, and many caregivers like Irena become lost in the complexity of care systems following the death of the patient for whom they are caring (Sealey, O'Connor, Aoun, & Breen, 2015). Their grief, exacerbated by the exhaustion and stress related to their care role, often goes unchecked and unsupported, and can result in continuing stress and mental health concerns following the patient's death (Boerner & Schulz, 2009).

The death of someone who has been a significant part of one's life is a normal but painful event that most people experience at some time (Shear, 2015). In spite of the pain of loss the majority of people adjust to their distress, integrating the loss into their lives as the intensity of the grief response recedes into the background, and people pick up the threads of life once more. However, for up to 10% of bereaved individuals, adjustment will be difficult (Aoun, Breen, et al., 2015; Currier, Neimeyer, & Berman, 2008). For this minority, the initial acute reaction fails to abate and remains at the forefront of daily life (Shear, 2015), and emotional suffering continues at an intense level for a protracted period of time (Currier et al., 2008). Such response in an individual is often referred to as complicated grief (CG) (Shear, 2015) or prolonged grief disorder (PGD) (Prigerson et al., 2009) and will be discussed in depth in Chapter Two.

The degree to which suffering affects a person's cognitive, behavioural or emotional responses, and the degree to which it affects his/her usual activities, such as social and/or occupational function, may warrant formal diagnosis and treatment to ameliorate suffering (American Psychiatric Association, 2013). In many cases, the death of a significant other with its associated grief cannot be known prior to the death; however, for a proportion of the population, grief following the death of a significant other due to a life-limiting illness can be reasonably expected. Many people with terminal or life-limiting illnesses are cared for by palliative care services within the health system and family caregivers are central to palliative care service delivery and philosophy (Thomas, Hudson, Trauer, Remedios, & Clarke, 2014).

## **Palliative Care**

Palliative care is the area of healthcare concerned with patients and families experiencing progressive life-limiting illness (World Health Organization, 2015). According to the World Health Organisation, the aim of palliative care is to prevent, or

relieve suffering by identifying potential problems in relation to physical, psychosocial and spiritual domains. Further, meticulous assessment should be undertaken to identify problems so that treatment can be initiated in a timely manner. Given the likelihood that a cure is improbable for patients with progressive life-limiting illness, treatment focus must change from traditional medicine's curative management, where psychosocial distress is of secondary importance, to reducing symptoms and managing distress (Mitra & Vadivelu, 2013). Most importantly, quality of life of patients and their families underpins palliative care philosophy (World Health Organization, 2015).

**Palliative care service delivery.** Palliative care services range from specialist palliative care services such as hospice in-patient units; community domiciliary services; or consultative services in hospitals which provide advice and support to staff delivering care in an acute setting, to primary care providers, such as general practitioners (GPs); and services that provide care to prisons or residential aged care facilities (Palliative Care Australia, 2005a). As the scope and range of palliative care is extensive and multifaceted, such supportive care across so many domains cannot be delivered without a holistic team approach by health professionals in order to address needs (Palliative Care Australia, 2005b). Such teams are usually referred to as interdisciplinary or multidisciplinary teams (MDT) and they play an essential role across all settings and in every stage of the palliative care trajectory (Mitra & Vadivelu, 2013). The teams comprise healthcare professionals with specialized skill sets, such as, but not limited to, physicians, nurses, pastoral care workers, counsellors, pharmacists, and social workers (O'Connor, Fisher, & Guilfoyle, 2006).

**Family caregivers in palliative care.** Patient and family caregivers are considered together as a unit of care during the illness (Fisher, 2003), with bereavement support after the patient's death an important objective of palliative care (McNamara & Rosenwax, 2010). In the palliative care setting, family caregivers may include any individuals in a significant relationship with the patient, such as relatives, friends, or partners who provide physical, psychosocial, or spiritual support and assistance to the person with a life-limiting illness (Hudson et al., 2012). While the inclusion of significant others within the unit of care is uncommon in many domains of health care, similar biopsychosocial approaches are usual in children's health (Kazak, 2006) and intensive care units, where family members are more likely to be required to make treatment or care decisions on the patient's behalf (Davidson et al., 2007).

However, in palliative care, alongside the decision-making partnership, family caregivers and significant others are thrust into the role of providing necessary primary care and support to the terminally ill patient, taking on unfamiliar tasks such as managing medications and complex patient care, with little or no preparation (Williams & McCorkle, 2011). Furthermore, due to the progressive nature of life-limiting illnesses, deterioration in patients' conditions often occurs rapidly and creates additional emotional strain on caregivers (Bentley, O'Connor, Breen, & Kane, 2014) who are often financially disadvantaged, socially isolated, and frequently unaware of available support services (Hudson et al., 2012).

Hudson, Thomas and colleagues (2011) suggest that many caregivers of people with a life-limiting illness suffer from exhaustion, burnout, social isolation and anxiety, experience sleep disturbances and poor health, and have an increased likelihood of having depression and anxiety. In a study of bereaved former caregivers, just over two thirds (71%) who were assessed as having prolonged or complicated grief admitted having suicidal thoughts and were less likely to seek support from health professionals (Lichtenthal et al., 2011). Higher rates of caregiver stress may negatively affect the patients for whom they are caring (Hudson et al., 2012). Mental health outcomes in bereavement are also likely to be worse for caregivers who have experienced a lack of psychological support during their care of the patient (Aoun, Grande, et al., 2015). The study by Aoun and colleagues found that caregivers rated being able to voice their worries and feelings as a high priority during the care trajectory. While health systems are ostensibly attempting to move toward patient-centred care, and families expect to be included as part of patient care and decision making, families regularly report feeling excluded when it comes to care of their loved ones (Davidson et al., 2007).

However, for palliative care services, the care of friends and/or family members is not always straightforward and, as Bell (2013) remarks, patients and families often perceive their relationships with health professionals as being difficult, and perceive staff as indifferent and unapproachable. Bell goes on to say that such relationships are influenced by the beliefs and attitudes of health care providers. Indeed, it would seem that after pain management, poor interactions with health care providers are the greatest source of distress for family members (Davis, Kristjanson, & Blight, 2003). Davis, Kristjanson and Blight (2003) identified that nursing staff

believed family conflict, communication within families, and denial in family members were among contributors to poor staff/family interactions. Such interactions, that lead family members to feel excluded from patient care and decision-making, adversely influence end-of-life and families' perceptions of a good death for the patient. Poor client/staff communications also undermine the family's supportive role in caring for the patient, which does not reflect the philosophy of palliative care that regards the family as the unit of care (Fisher, 2003).

**Caregiver support.** It is clear that caregivers need support to assist in the ongoing care of the patient; however, their needs are often overlooked by palliative care services (Aoun, Grande, et al., 2015; Hudson et al., 2012), with no formal assessment of their needs (Ewing & Grande, 2012). Bereavement support offered by palliative care services, in Australia and other developed countries, is beset by a number of issues, particularly in relation to the assessment of bereavement risk for caregivers, and the provision of appropriate bereavement care (Breen, Aoun, O'Connor, & Rumbold, 2014; Field, Payne, Relf, & Reid, 2007; Schut & Stroebe, 2011). Bereavement support is often provided to all bereaved individuals rather than targeting those in need. Additionally, funding and staffing constraints impact upon the provision and evaluation of services (Aoun, Breen, O'Connor, Rumbold, & Nordstrom, 2012). Providing blanket support to all caregivers results in ad hoc delivery of bereavement services, where some clients (possibly those with greatest need), miss out on support, while others may have unneeded services imposed on them (Kristjanson & Lobb, 2004).

Given the link between higher rates of psychological distress, poor health outcomes and caring for a patient throughout a life-limiting illness (Thomas et al., 2014), it would seem prudent for palliative care services to monitor caregivers during the patient's illness by assessing or screening grief with the aim of either avoiding, or at least minimising, complicated or prolonged grief reactions into bereavement and in future.

### **Aims and Objectives of the Present Study**

The overall purpose of this study was to improve bereavement risk assessment practice in palliative care services for caregivers supporting loved ones or family members with life limiting illness whilst under the care of a palliative care service.

Using action research (Hart & Bond, 1995) as an overarching methodology, the aim was to develop and trial a bereavement risk assessment model to interface with Western Australian bereavement support services within the context and ethos of each service.

The issues relating to bereavement risk assessment and support were examined in collaboration with palliative care stakeholders, (service providers, health professionals, bereaved former caregivers and caregivers) in order to develop a feasible bereavement risk assessment model congruent with existing policy and guidelines (Hall, Hudson, & Boughey, 2012; Palliative Care Australia, 2005b). The bereavement risk assessment model was based on a three-tiered public health model aligning need with support (Aoun, Breen, et al., 2012), and was intended to interface with available bereavement support services compatible with the context of each service.

It was anticipated that existing bereavement measures or screening instruments for possible use in the model would be identified through a scoping review of the literature. Current assessment practice by palliative care services was reviewed through a stakeholder group of palliative care health professionals and a bereaved former caregiver. The barriers to, and facilitators of, bereavement risk assessment practice were explored in the group's discussions. The bereavement risk assessment model that was developed in response to stakeholder input was piloted on caregivers before being evaluated with the perspectives of the caregivers, palliative care health professionals and service management. Finally, a summary report of findings and recommendations was drawn up for dissemination to the palliative care stakeholder community.

### **Research Questions**

- Can bereavement risk assessment for caregivers be carried out with existing psychometrically sound instruments in palliative care settings?
- Can an optimal time frame for the assessment of bereavement, from the patient's admission to the service to following the patient's death, be established with the use of such a model?
- Will such an assessment model accurately identify those 'at risk' individuals who require additional follow-up or support?

- Will caregivers caring for a patient in a palliative care service find the assessment acceptable to use?
- Will palliative care teams find the proposed bereavement assessment model acceptable for use?
- Will the proposed model be acceptable at an organisational level in terms of resources (personnel and cost) and in terms of staff education and ongoing support?
- Could this model work effectively across a variety of palliative care service models and settings in WA?
- If successful, can such a model guide policy in palliative care organisations, and be parsimonious and sustainable?

### **Significance of this Research Study**

In order to match support with need, assessment of caregivers' bereavement status is a matter of priority. This has been advocated by national standards (Palliative Care Australia, 2005b) and bereavement guidelines governing palliative care (Hall et al., 2012). By assessing caregiver bereavement needs, the provision of timely and appropriate bereavement support for those with complex needs, and those at risk of developing complex needs, may prevent further distress (Currier et al., 2008). Findings from a study using grief therapy for families prior to the patient's death showed a reduction in distress and depression up to 13 months post-death (Kissane et al., 2006), lending weight to an argument for early assessment and intervention in family caregivers. In particular, assessment that facilitates appropriate support may ameliorate the extreme distress suffered by a minority of bereaved caregivers and could save the lives of those at heightened risk of suicide (Ajdacic-Gross et al., 2008).

It is expected that the introduction of a bereavement risk assessment model should standardize assessment protocols within each palliative care team (Hall et al., 2012). Given that the assessment of caregiver needs is in the top ten indicators of quality end-of-life care, standardizing assessment should streamline current practice, thus saving time and allow staff more focus on care for patients at end-of-life (Hudson et al., 2012). Standardized bereavement risk assessment would also create uniformity

across services within the system and decrease the likelihood of people missing out on support between services.

A bereavement risk assessment model should also result in more parsimonious use of resources for palliative care services by allowing palliative care services to forge referral pathways to support services between the various support service providers in the community (Breen et al., 2015; Rumbold & Aoun, 2014). Positive outcomes from the present study may enable services to establish procedure and policy in relation to bereavement risk assessment, leading to greater clarity for the development of a service provision protocol based on identified need (Aoun, Breen, & Howting, 2014). Ultimately, it is hoped that bereavement care, modelled on this framework, will flow on to the wider community, so that all organizations dealing with the bereaved, such as grief related to suicide, or road trauma for example, might benefit from practice established in palliative care (Aoun, Breen, et al., 2012).

### **The Researcher**

In action research there is a close association between the researcher and the subject of his or her research and, as Hockley, Froggatt, and Heimerl (2013) state, such research "...is not value-free but will inevitably be tied up with their own previous experience alongside that of co-researchers in the project from the clinical setting" (p. 8). Corbin and Strauss (2008) add that "all reflective enquiry starts from a problematic situation" (p.3). The researcher is primarily committed to bringing about positive change by working within the stakeholder group in an egalitarian fashion (Lincoln, 2001) and, as such, robust self-enquiry must be practiced by the researcher (Marshall, 2001). Marshall notes that action research is a personal process given the researcher draws on previous knowledge and experience in the process of enquiry. The following paragraphs are intended to give the reader insight into my reflections as to why I chose this topic as an area of research.

Having worked in palliative care exclusively over the past two decades, both as a registered nurse and as an allied health professional and counsellor, I am well aware of the many issues faced by services. I firmly believe we do palliative care well; that is, the aspect of palliative care that supports patients who are facing life-limiting illness. What I believe we don't do as well, is care for the family caregivers, particularly following the patient's death. Being born to grieving parents, I have seen



first-hand the ongoing and unremitting suffering of those with deep-seated grief, who might have had the opportunity to lead different lives if appropriate and timely support had been available.

In my palliative care work, I had long been frustrated by the decision making process at weekly multidisciplinary team meetings to discuss family caregiver bereavement support needs. I could understand with my “nurse” hat on that nurses make observations and act on those observations. For example, a nurse may observe poor circulation underneath a freshly applied plaster in an orthopaedic patient, and would be obliged to take action so as to avoid longer term serious consequences. However, with a “counsellor/psychology” hat on, I am dismayed that the same observational method is applied to emotional states. A counsellor would not assume to know what an individual’s internal emotional or cognitive state might be by mere observation. I am also concerned that caregiver reactions and behaviours are noted by staff and attributed with meaning without caregiver knowledge or consent. While working in palliative care I advocated that caregivers be asked directly about their feelings and coping; however, staff believed that caregivers would be burdened if asked to complete a self-report inventory and would not give meaningful responses and, as such, it would be upsetting for caregivers and an additional administrative encumbrance for staff. Believing that caregivers would welcome an opportunity to express their feelings, my prime motivation in this study was to find from caregivers themselves whether or not they would accept using a brief grief self-report measure.

Prior to the commencement of this study there had been numerous meetings between local palliative care services in relation to bereavement support. It was clear standards and policies would become increasingly important in relation to accreditation and funding in the foreseeable future. Concern had also been raised by service providers that there was no known validated assessment tool with which to begin the process of providing bereavement support. At this time, local palliative care researchers conducted a scoping study of palliative care services in Western Australia, which resulted in an extensive collaborative research agenda where local services placed bereavement risk assessment as a priority (Aoun, O'Connor, & Breen, 2012).

In an initial review of the literature I was surprised that the same local issues were also posing the same problems in other developed countries (Agnew, Manktelow,

Taylor, & Jones, 2010). What was even more surprising was that staff had been expressing dissatisfaction with observational checklists in the 1980s, unsure of whether or not they were identifying caregivers in need of bereavement support (Payne & Relf, 1994). Twenty years later nothing had changed. It would be inconceivable that similar responses would occur with any other physical condition. Would we have the same improved outcomes today for cancers and heart disease, for example, if 1980s assessments and treatments were still regarded as gold standard? In retrospect, it pointed to a more fundamental and more complex issue that the development of a bereavement risk assessment model was not going to remedy easily.

However, given palliative care service providers had expressed a need to address bereavement risk assessment I believed that the timing was right for this study. I also felt optimistic that collaboration with local services would result in a positive outcome; an assessment protocol that would be congruent with standards and policy, as well as an assessment protocol that would be feasible in clinical practice.

### **Structure of the Thesis**

The present chapter introduced the context of the study and gives an overview of palliative care, its underlying philosophy, the settings where it is practiced, the health care professionals who provide care to the patients and their caregivers, and some of the issues relating to caregiving. It also gave the reader a brief insight into the researcher's orientation to the research and motivation to engage in the study.

Chapter Two reviews the literature and is divided into three parts. The first section details bereavement standards and policies relating to palliative care and illustrates the gap between policy and present practice of bereavement support, which will be discussed in greater detail. The second section focuses on grief and bereavement, and highlights the difficulties associated with the assessment of grief and bereavement, and gives an overview of the present diagnostic categories and treatment foci. The third section of the literature review looks at possible ways of overcoming the challenges discussed and concludes with the rationale for the study.

Chapter Three focuses attention on the research design, giving an in-depth discussion of the overarching action research methodology (Hart & Bond, 1995) and why it has been chosen as a best-fit for this study. The philosophy underpinning action

research is detailed. Discussion will also centre on the various methods used for each of the action research phases throughout the study. Ethical considerations will also be discussed, as well as reflexivity and the internal personal processes that have shaped the study.

Given that information gathering is an integral aspect of action research (Hart & Bond, 1995), Chapter Four is a published article which details the scoping review of the literature undertaken to identify existing grief and bereavement measures for potential use in the bereavement risk assessment model (Sealey, Breen, O'Connor, & Aoun, 2015). Each of the 19 measures identified is discussed at length in the context of caregivers and palliative care.

Chapter Five likewise is a published article discussing focus group data from palliative care stakeholders including health professionals and a bereaved former caregiver. These reference group data were analysed thematically and highlight the barriers to bereavement risk assessment in palliative care. The barriers are discussed in detail and the paper concludes with a way forward; to develop a measure that would be feasible for use in palliative care (Sealey, O'Connor, Aoun, et al., 2015).

Chapter Six details the development of a new bereavement risk assessment measure suitable for palliative care use. The five stages of developing the measure are discussed, from a review of grief literature to determine risk factors and predictors of complicated or prolonged grief, through working with an advisory group of bereavement service providers and bereaved former caregivers, to the pilot of the measure at three service models of palliative care.

Chapter Seven discusses the evaluation of the new grief measure by the caregivers who trialled the new measure, and the palliative care health professionals who were involved in the pilot. This chapter illustrates the differences in the service models of care, further highlighting the issues identified by the earlier reference group participants in relation to risk assessment barriers.

Finally, Chapter Eight concludes the thesis with a discussion of the study as a whole. The chapter discusses the strengths and limitations of the research, and in particular looks at the contribution the study has made to palliative care research and

the implications it has on practice, policy and theory. Recommendations will be proposed for future research in this area.

## **CHAPTER TWO**

### **Literature Review**

“Well, everyone can master a grief but he [sic] that has it.”

- William Shakespeare,

*Much Ado About Nothing* (Act III, Scene II, Line 26)

#### **Chapter Overview**

Death and dying, grief and bereavement, and palliative care can be confronting subjects for some people and can engender discomfort for others (Seymour, French, & Richardson, 2010). This review of the literature covers three broad sections. The first highlights the gaps between the present practice of bereavement assessment and support in palliative care and policy. The next section discusses the complexity of grief and bereavement in relation to assessment and the provision of bereavement support to the minority of at risk grieving individuals. Finally, the third section examines possible solutions to the complex issues raised in the first two sections. Rationale for the research study will conclude the chapter.

#### **The Gap Between Present Bereavement Support, Practice, and Policy**

As highlighted in Chapter One, associations have been established between poorer physical and mental health in individuals caring for a loved one or family member with a life-limiting illness (Thomas et al., 2014). It is therefore essential that palliative care health professionals assess risk prior to the patient's death, identify those caregivers who have a possibility of developing complicated grief and, furthermore, to know when to connect caregivers to appropriate professional support (Boerner, Mancini, & Bonanno, 2013). However, as touched upon in Chapter One, the assessment of bereavement risk and the provision of bereavement support by palliative care services are affected by numerous difficulties (Breen, Aoun, et al., 2014; Field et al., 2007; Schut & Stroebe, 2011).

#### **Current Practice of Bereavement Risk Assessment in Palliative Care**

Research has consistently demonstrated that bereavement support in palliative care tends to be delivered on a piecemeal, ad hoc basis without formal assessment of

risk or need (Agnew, Manktelow, Haynes, & Jones, 2011; Aoun, Breen, Rumbold, & Howting, 2014; Breen, Aoun, et al., 2014). This informal process of assessment tends to result in support being offered to those who may not need it, while others who would benefit, miss out (Hudson, Trauer, et al., 2010; Kristjanson & Lobb, 2004; Lichtenthal et al., 2011).

**Changes in risk assessment over time.** In Australia, in the early 1990s only one third of palliative care services reported using a formal assessment of risk (Payne & Relf, 1994). In 2003 a survey of UK hospices found that 43% of in-patient settings used a formal risk assessment tool in tandem with informal assessment by nursing staff (Field, Reid, Payne, & Relf, 2004; O'Connor, Abbott, Payne, & Demmer, 2009). The study found that clinical judgements were usually recorded on written checklists (formal risk assessment), with each individual's needs discussed as an informal assessment at multidisciplinary team meetings (Agnew et al., 2010). By 2008 Mather, Good, Cavenagh, and Ravenscroft (2008) found that just over two thirds (69%) of Australian services reported assessing for 'complicated grief'. Of these, 57% of metropolitan services, and 68% of regional services used a risk assessment tool, often in the form of an in-house observational checklist, while others assessed risk based on either multidisciplinary team opinion, or the appraisal of a single staff member. In 2009, in a comparison of bereavement services provided in palliative care settings, O'Connor, Abbott, Payne, and Demmer (2009) confirmed that bereavement risk assessment was largely an informal process in Australia, the United Kingdom (UK) and the United States of America (USA).

A recent Australian population-based survey indicates there continues to be a wide variation in the way bereavement risk is assessed by palliative care services. The research by Aoun and colleagues (2015) shows around two-thirds of palliative care services assess bereavement risk before the patient's death and that assessment often involves the use of non-validated measures, and/or staff opinion, indicating little change since Mather and colleagues study of 2008. The apparent increase in the practice of bereavement risk assessment between the 1990s and the mid-2000s indicates that services may deem assessment of bereavement risk as being important, however, it remains that what the services regard as a formal assessment of bereavement risk is based on observational checklists and staff opinion, rather than the use of a validated, psychometrically sound grief measure.

**The process of risk assessment in practice.** Within multidisciplinary teams, nursing staff are the most likely to carry out bereavement risk assessment (Field et al., 2004; Mather et al., 2008). Assessment accuracy depends on nursing staff having the skills and psychosocial education to carry out assessments (Relf, Machin, & Archer, 2010). Such assessments, by observing family interactions and emotional responses recorded on in-house forms, are usually filled-in close to the time of death, and are often found to contain incomplete or ambiguous information (Agnew et al., 2011). Agnew and colleagues questioned the reliability of staff observational information given that caregivers may be considerably distressed at the time of the patient's death with the finality and realisation that their loved one or patient has died. Such distress at the time of a death does not necessarily indicate the presence of complicated grief (Rando, 2013). Agnew et al. also voice concerns that caregivers are not aware that they are being assessed and that the observations are recorded without caregiver consent. They suggest caregiver consent be obtained before undertaking assessment, which was also recommended in the recent Victorian standards (Hall et al., 2012).

**Documentation of risk assessment.** However, documentation is problematic given caregivers are not clients of a palliative care service, which creates confusion in relation to duty of care (Agnew et al., 2011). Agnew and colleagues noted that the 2004 NICE Guidance Standards in the United Kingdom (National Institute for Clinical Excellence, 2004) recommended bereavement support to caregivers, yet failed to address the issue of documentation. Likewise, the Victorian standards state “a structured risk assessment based on conversational exploration of the risk factors...requires structured documentation, review in team meetings and the use of family assessment” (Hall et al., 2012) p.12) and also fails to address where that documentation should be filed. Australian Government regulations (Australian Government National Health and Medical Research Council Privacy Committee, 2004) relating to health information state that a service should not collect information unless the individual has consented, with the knowledge of why the information has been gathered, and to whom the information will be disclosed and why. The service must also have guidelines in relation to how long the information should be retained and allow individuals to access the information, which may be governed by legislative regulations. However, for palliative care services, the terminally-ill patient is the client,

creating a medico-legal grey area in relation to caregivers and documentation (Agnew et al., 2011).

### **Current Bereavement Support in Palliative Care**

With regard to the provision of bereavement support services, research by Mather and colleagues (2008) found that 95% of Australian palliative care services offered some type of support to bereaved families, which was an increase from just over 50% of services offering bereavement support in 1992 (Payne & Relf, 1994). In both studies, services varied in the types of support offered, with support including the issuing of information packages, follow-up telephone calls, cards and letters to the bereaved, memorial services, informal gatherings, and group or individual therapy (Mather et al., 2008; Payne & Relf, 1994). These supports are typical of those used in palliative care settings in countries such as the UK (Field et al., 2004), USA (Demmer, 2003), Japan (Matsushima, Akabayashi, & Nishitaten, 2002), and Ireland (Roberts & McGilloway, 2008). Uncertainty surrounds how helpful caregivers find such support (Mather et al., 2008), as well as the length of time bereaved caregivers should remain under hospice care, with many services lacking clear policy in relation to caregiver follow-up (Aoun, Breen, Rumbold, et al., 2014).

In keeping with hospice philosophy, many hospices tend to offer blanket bereavement services, thus allowing people to access support if they wish (Reid, Field, Payne, & Relf, 2006). Payne and Relf (1994) suggest that offering support to all removes the burden of decision from staff, mitigating the need to deny access to someone in need of support. Aoun and colleagues (2015) also found that palliative care services tended to provide bereavement services based on a one-size-fits-all approach, rather than link with other community bereavement service providers.

**Caregiver help-seeking behaviour.** Research however, indicates that the majority of bereaved people, particularly those in most need, do not seek help for their grief (Breen & O'Connor, 2007; Currow et al., 2008). Lichtenthal and colleagues (2011) found that just over half of bereaved former caregivers, 16% of whom met criteria for prolonged or complicated grief, believed they had no mental health concerns and as such, did not require support services. Others relied on support of family, friends or church community. Other barriers cited in the study were: the cost of services; having insufficient time to access a service; being unaware that services



existed; the belief that treatment is ineffective; and embarrassment about asking for help. A more recent population-based survey challenges the assumption that people do not access grief support, finding that those at high risk of complex grief issues reported accessing the same types of support that others used but they believed the available support was insufficient for their needs (Aoun, Breen, et al., 2015).

It is clear that palliative care and hospice services in developed nations have very similar approaches to bereavement care, both in assessment and provision of bereavement support (Breen et al., 2014). A survey of palliative care services conducted in the UK in 1992 revealed dissatisfaction with the use of checklists and open-ended questions and whether or not the assessments were accurate in detecting those caregivers in need of support, as well as concerns about the adequacy of bereavement follow-up services (Payne & Relf, 1994). It is of concern that little, if anything, has changed with regard to bereavement risk assessment over the past 20 years.

When caregivers are not directly addressed in relation to theirs or the patient's needs, it is understandable that many families describe feeling excluded from the care process (Davidson et al., 2007). As mentioned in Chapter One, there has been a recent shift in health service philosophy towards providing patient-centred care which embraces inclusiveness of families in the planning and implementation of patient care. Excluding family members does not reflect palliative care philosophy which places emphasis on the importance of the family to the patient's overall care and wellbeing (Fisher, 2003). As such, policies and standards are necessary to guide the provision of consistent care across palliative care services (Palliative Care Australia, 2005b).

### **Policy and Standards Relating to Bereavement Care in Palliative Care**

The National Standards Assessment Program (NSAP) applies to all Australian palliative care service providers. Standard 8 advocates that patients, caregivers, and family be provided with information on grief and the availability of support services (Palliative Care Australia, 2005b). This document broadly outlines the need for bereavement risk assessment and the provision of bereavement support, information needs, referral processes, and the training and supervision requirements of health professionals who provide bereavement care; however, it lacks detail in relation to these points.

**International standards.** Such standards exist in other countries as a benchmark for quality end-of-life care (Hudson et al., 2012). For example, in the United States of America, Guideline 3.2 of the psychological care domain in the *Clinical Practice Guidelines for Quality Palliative Care* (National Consensus Project for Quality Palliative Care Task Force, 2009) states that a bereavement program should be available to patients and their families based on an assessed need for bereavement support, and that services should be available to families for at least 12 months following the death, or for as long as needed. The standard also outlines training and supervision of staff and volunteers and advocates that referral should be made to specialist health professionals if needed. *Bereavement Care Service Standards* in the United Kingdom (Bereavement Services Association & Cruse Bereavement Care, 2013) were developed as a guide for ‘gold standard’ practice in order to bridge the gap that had been identified between the varying needs of bereaved people and the availability of a range of bereavement support services. The seven standards relate to: planning services in response to identified need; awareness and access in relation to service provision; assessment protocols to assess individual bereavement support needs; support and supervision so that staff and volunteers provide safe bereavement services; ongoing education and training for service providers; resources that are responsive to needs; and the review and ongoing monitoring of services. The standards take an integrated approach to the delivery of support, yet adapt to individual needs and local services and, as such are a benchmark for use by services nationwide.

These international guidelines and standards are more specific about the application of bereavement risk assessment in relation to support than the Australian NSAP standards (Palliative Care Australia, 2005b). Recognising the essential role of caregivers in supporting patients, and acknowledging the range of caregiver needs, guidelines in the United Kingdom recommend that palliative care organisations appoint a staff member to coordinate culturally appropriate caregiver support before and after the patient’s death (National Institute for Clinical Excellence, 2004). Conceding there is variability in bereavement service provision, the guidelines also propose that palliative care services look to other services in the community, such as volunteer led support, peer-support groups or professional services, to provide the range of different types of assistance family caregivers may need, and suggest a three-tiered model of bereavement support.

**Australian guidelines and standards.** In light of the current problems with informal assessment and lack of referral pathways to bereavement services (Breen et al., 2014), Hudson and colleagues (2012) developed detailed guidelines for psychosocial and bereavement support for family caregivers. The recommendations were developed in consultation with an advisory group of key international and Australian stakeholders following a survey of Victorian palliative care services and a review of literature. The guidelines were intended primarily for health care professionals working in specialist palliative care services in Australia but are also useful for other health care providers such as general practitioners, who may provide palliative care during the course of their work.

Following the development of these guidelines, the *Bereavement Support Standards for Specialist Palliative Care Services* (Hall et al., 2012) was published in 2012 to be applied broadly in adult, government-funded, specialist, palliative care services in the state of Victoria, Australia. The standards have provided an initial, much-needed framework to address the many complexities of bereavement care, with the recommendation of 11 standards which include screening and assessment, bereavement support strategies, and referral to external support agencies if required. Recognising the lack of any one validated screening measure, the standards recommend that a structured, conversational exploration of complicated grief risk factors be undertaken and documented with the caregiver. Assessment should commence at the patient's admission to the service, and should be ongoing throughout the patient's length of stay in the service. As soon as possible after the patient's death, trauma in the peri-death period should be assessed, with further contact at twelve weeks post-death to check if further follow-up will be required. For those identified as having a greater risk of complicated grief, the standards recommend further assessment at six months after the death. The standards recommend that at any time throughout the pre and post-death period, any caregivers indicating suicidal, self-injurious behaviour, or risk of harming others should be urgently referred to appropriate services such as hospital emergency or mental health agencies (Hall et al., 2012).

### **Possible Explanations for the Gap Between Policy and Practice**

Varying reasons have been postulated for the reasons why bereavement risk in caregivers continues to be assessed in such an informal ad hoc manner (Agnew et al.,

2011; O'Connor et al., 2009). These may be grouped into four issues; grief measures; changing workplace trends; communications with patients and families and; understandings of grief.

**Grief measures.** In terms of formal assessment, there seems to be a paucity of established bereavement measures developed for the palliative care setting (Ewing, Brundle, Payne, & Grande, 2013). In a systematic review of literature, Hudson and colleagues (2010) attempted to clarify the complex range of issues that relate to bereavement risk assessment in palliative care. Sixty-two instruments were identified; mostly related to satisfaction with services, perceived quality of life, having needs met, or burden of care. Eighty-nine percent of instruments were self-report and the majority of instruments were created for research rather than clinical application. No instrument was found to identify those likely to be at risk of developing psychosocial problems in the pre-death phase. These researchers have therefore recommended that further work is needed in bereavement risk assessment, and that caregiver risk needs to be assessed at different points in time, namely during contact with the palliative care service prior to death, during early bereavement, and at six months or more to detect complicated grief. To date there has been no systematic review of grief or bereavement instruments or measures identified in a risk assessment model as proposed in the Bereavement Support Standards for Specialist Palliative Care Services (Hall et al., 2012). Alongside the identification of grief instruments, there also needs to be an examination of how the identified instruments might fit into palliative care clinical practice.

**Changing workplace trends.** Changing trends towards later referral to palliative care services and shorter lengths of stay, means that staff can no longer undertake an informal assessment and build a family picture, as was done in the past (Agnew et al., 2011). Heavy workloads and shortage of staff with knowledge or skills in assessment is also problematic in conducting assessments, particularly when staff development or educational opportunities are limited (Payne & Relf, 1994). Payne and Relf (1994) further report that nurses are uncomfortable asking what they regard to be intrusive, personal questions and for these reasons informal assessment, based on observation is preferred because it fits in with staff routines and documentation protocols.

**Communications with patients and families.** Health professionals face a number of challenges in relation to communicating with family members; these include avoidance of anxiety provoking situations, feeling ill-prepared to communicate with families, and inexperience with death and dying (Powazki et al., 2014). Deffner and Bell (2005) and Payne and Relf (1994) also suggest, that staff prefer to intuit caregiver needs in order to avoid the discomfort of asking personal questions. Deffner and Bell (2005) argue that westernized culture propagates attitudes that regard death as a failure, leading to a sense of lack of control. These authors state that such attitudes can create anxiety in health professionals, who believe they should be able to manage such situations more adeptly. Their research found that when nurses were given communication skills education, levels of anxiety decreased. Similarly, Wessell and Rutledge (2005) found that less experienced nurses who care for the dying had greater anxiety and discomfort about communicating with families, and felt more prepared following communication skills education. Education to enhance nurse/patient/family communications at end-of-life has been lacking in the past and needs increased focus (Powazki et al., 2014).

A Western Australian study by Davis, Kristjanson, and Blight (2003) found that uncertainty about a family's style of interaction, for example, in family situations where conflict is high, or where there was non-preparedness for the patient's death also contributes to staff having difficulty communicating with family caregivers. Team communication, particularly in relation to treatment planning and communicating the plan to a family, was also found to be the most pronounced factor in the same study, especially when a new or inexperienced staff member enters a team. Additionally, the study found a trend towards more acute intervention in palliative care has led to increased workloads and decreased availability of time to spend with patients and families. O'Connor and Fisher (2011) suggest that blurred boundaries between multidisciplinary team members' roles also contribute to a tendency for staff team members to believe they have privileged patient/family knowledge, leading staff to gather information intuitively based on their professional experience and knowledge. These researchers also found that health professionals found it difficult to take on other opinions within the team because they were confined by the perspective of their own discipline.

**Understanding grief.** A reluctance to address caregiver emotional needs may also arise from health professionals' lack of understanding about grief and the grieving process. Scant attention is paid to grief education in many university health disciplines courses, resulting in health professionals being ill-prepared to provide grief support (Breen, O'Connor, Hewitt, & Lobb, 2014; Wright, 2011). It seems that the present challenges in relation to bereavement risk assessment faced by palliative care multidisciplinary team members are complex and multi-faceted; however, it is possible that grief too is a substantial challenge in its own right, even though it is a commonly experienced event that will affect everyone at some time across the lifespan (Rubin, Malkinson, & Witztum, 2012).

While grief and mourning are universally experienced phenomena, individual expressions are mediated by factors such as culture, ethnicity, gender, age and religious beliefs. Additionally, social factors such as education and socioeconomic status also influence a griever's response to his or her loss (Granek & Peleg-Sagy, 2015). Often, assumptions about the individual experience of grief are based on a supposedly universal White European male norm (Granek & Peleg-Sagy, 2015) and research dominated by White, North American, middle-class samples of widows (Breen & O'Connor, 2007) where conclusions overlook the influence of socio-cultural and/or environmental factors.

## **Grief and Bereavement**

Understandings of the complex nature of grief and bereavement can be a challenge to the effective provision of support to those at risk of poor bereavement outcomes (Rando, 2013), and deserves attention when considering bereavement risk assessment.

**Grief work, stages and task theories.** Building on Freud's (1917) concept of mourning work to heal grief, Bowlby and Parkes (cited in Maciejewski, Zhang, Block, & Prigerson, 2007) suggested that adjustment to grief required the negotiation of a series of stages. According to Stroebe and Schut (1999) this concept of grief work has been poorly operationalized and there is a lack of evidence for its efficacy or its applicability across cultures or gender. Worden (2010) considers grief work is an active process of working through a series of tasks. Kübler-Ross (1973) believed that those with life-limiting illness experience five stages of reactions as they negotiate

approaching end-of-life, ranging from denial to acceptance. Kübler-Ross proposed these ideas to understand the dying process; however, end-of-life issues have been merged with bereavement in health professional training and, as such, contribute to misunderstandings by health care providers (Center for the Advancement of Health, 2004).

The popular belief that grief must be worked through in a prescribed manner has taken firm hold with laypersons, those in the media and by some who provide bereavement services, leaving bereaved people feeling at fault when their grief does not fit with the popular view (Breen & O'Connor, 2007; Neimeyer & Sands, 2011). Linear stage theories omit attention to the various losses and numerous stressors and adjustments that a bereaved person undergoes, and along with a realisation of the complexity of loss and stress related grief, has prompted a paradigm shift away from linear stage theories towards theories that focus on the process of bereavement (M. Stroebe & Schut, 1999). Two such theories are the Two-Track Model of Bereavement (Rubin et al., 2009; Rubin, Malkinson, & Witztum, 2012) and the Dual Process Model of coping with bereavement (M. Stroebe & Schut, 1999).

**The Two-Track Model of Bereavement.** The Two-Track Model (TTMoB) was developed in the early 1980s by Rubin in response to deficits in earlier theories, and to explain the intricacy of loss (Rubin et al., 2012). Over time beliefs had changed from the need to detach emotional energy from the deceased, to ways in which people may re-shape and continue bonds with their loved ones. Rubin was also concerned with the impact that bereavement had on a person's function, health and well-being, given the established links with somatic complaints and mental health problems. The Biopsychosocial Function (Track I) covers 10 domains relating to affective, cognitive, social, meaning, experience of self and somatic experiences. Relationship with the Deceased (Track II) is also concerned with 10 domains relating to emotional involvement and relationship prior to the death, perceptions and imagery. Both tracks consider difficulties and individual strengths (Rubin et al., 2012), and both biopsychosocial function and the continuing bond with the deceased must be considered in tandem to measure the grief response and plan intervention (Rubin, Malkinson, & Witztum, 2008). The TTMoB offers a framework that can be applied to various theoretical treatment perspectives; for example, using a cognitive behavioural

perspective or a psychodynamic-existential viewpoint (Malkinson, Rubin, & Witztum, 2006).

**The Dual Process Model of Bereavement.** Drawing on cognitive stress theory (Lazarus & Folkman, 1984) and the stress response syndrome (Horowitz, 1976), Stroebe and Schut (1999) formulated the Dual Process Model (DPM) explaining the interplay between the many stressors caused by bereavement and the griever's coping strategies, which may range from adaptive to maladaptive (M. Stroebe & Schut, 2008). Stress response theory holds that reactions to an event may also involuntarily vacillate between intrusive re-experiencing and avoidance as a means of coping; with grief the vacillation occurs between confrontation and avoidance. The DPM is therefore built on the notion of competing stressors in the domains of loss and restoration activities, whereby the bereaved switches focus in dealing with stressors. Grief is the primary stressor at the heart of loss-orientation, and is primarily emotional. Restoration-orientation centres on the bereaved person's efforts to adapt to life without the deceased, and requires focus on secondary stressors such as employment, or activities associated with daily living. Both domains are stressful, as the bereaved oscillates between the two, however, the oscillation does provide relief from one domain while attention is focussed on the other.

Over time, the dynamics of the process will change so that the individual gradually accommodates the loss (M. Stroebe & Schut, 1999). This model offers insight into grief processes for both researchers and clinicians. In cases of ongoing intense grief, the bereaved may focus on the loss rather than attempt to deal with restoration. Others may focus on restoration, occupying themselves with practical matters in an attempt to avoid the emotional aspects of the death. For others, such as those experiencing traumatic grief reactions, the problem may lie with the process of oscillation itself whereby the process of switching between loss and restoration does not occur smoothly, for example in the case where one may experience intrusive thoughts, and/or avoidance of reminders (M. Stroebe & Schut, 2008). Since the formulation of DPM, much research has shown support for the applicability of the model. For example, Shear, Frank, Houck, and Reynolds (2005) gauged the efficacy of Complicated Grief Treatment (CGT) against Interpersonal Psychotherapy (IPT) using the DPM as a framework for the intervention, and CGT was found to be more effective than IPT. The DPM also accords with cultural expressions of grief where society may



impose rules on the bereaved, biased towards either loss or restoration (Klass & Chow, 2011).

**Attachment theory.** Bowlby's theory of attachment (Bowlby, 1980) also offers insight into bereavement distress (M. Stroebe & Schut, 1999; W. Stroebe & Schut, 2010), holding that individuals have an innate desire for connection with significant others. Threats to this connection will likely trigger protest and, in the case of bereavement, the individual may experience ongoing distress (Bowlby, 1980). Those who have not developed secure attachment to a parental figure early in life are at greater risk of complex grief issues over time (M. Stroebe, Schut, & Boerner, 2010).

**Theories of meaning-making.** According to Neimeyer and Sands (2011) the death of a loved one affects one's self narrative, triggering a search for meaning as the bereaved person readjusts to life. These authors suggest deaths that are expected and normative are less likely to prompt a search for meaning, while deaths that challenge one's worldview, for example a death by violence, will require greater adjustment.

### **Popular Assumptions about Grief**

Breen and O'Connor (2007) suggest that the theories outlined above have shaped our understanding of grief. The dominant understanding of grief is that: grief follows a common pattern; grief is of short duration and ends; grief is a linear process of discrete stages; grief can be worked through; grief commences when a death is anticipated; meaning and positive outcomes must be sought; detachment from the deceased should be achieved and; ongoing grief that does not conform with these parameters is abnormal (p. 200 - 201). Wortman and Silver (1989) also hold that such widely held erroneous assumptions have become enduring myths that will be difficult to change because people have a tendency to resist evidence to the contrary. Such myths, they say, are potentially harmful to the bereaved resulting in inappropriate support from both social networks and professional service providers.

Erroneous views, when held by health professionals, deem that those whose grief differs from the dominant discourse are regarded as having abnormal or pathological responses to grief (Breen & O'Connor, 2007; Klass & Chow, 2011). However, Engel (2012) points out that grief has many similarities with physical diseases, such as a known cause and symptomatology that may cause functional

impairment, runs its course, and may be amenable to treatment. He supports this argument by stating that bereaved people often consult doctors for assistance with their troublesome symptoms. In a study of public opinion about norms and expectations of grief, Penman, Breen, Hewitt, and Prigerson (2014) found that three quarters of participants believed that grief could be regarded as a mental health disorder, if it remained at an intense level and affected function. Rando (2013) is of the opinion that many clinicians would also support a complicated or complex grief diagnostic category and a recent survey of counsellors and psychologists found that 57.5% believed that recognition of complicated grief would lead to improved treatment for such clients (Ogden & Simmonds, 2014). These debates highlight the complexity of grief and the many issues in need of consideration in the assessment of bereavement.

### **Grief as Normal or Complex?**

The expression of grief, even in the early Freudian psychoanalytic tradition, was problematic because there was no means of distinguishing between what could be considered 'normal' in relation to 'abnormal' or pathological grief (Granek, 2010). According to Granek, Freud saw most conditions as existing on a continuum with normal or non-pathological responses at one end and abnormal and pathological on the other; where one may be at any time was apt to shift over time depending on what was happening to the person. Research by Holland, Neimeyer, Boelen, and Prigerson (2009) lends weight to the idea that grief responses may lie on a continuum with resilience and adaptive coping at one end, and debilitating and protracted suffering at the other. A bereaved person's initial reaction to loss is described by Shear (2015) as "...a strong yearning, longing, and sadness," (p.153) where the individual compulsively thinks about the deceased, yet with a sense of disbelief that their loved one is no longer present. She states that individuals may withdraw from their usual pursuits, often exhibiting sadness, depression or anxiety, accompanied by physical symptoms, such as changes in cardio-vascular function, sleep disruption, and increased release of cortisol.

Research indicates that there is a minority of bereaved individuals who fail to move from the initial acute phase of grief who become debilitated by grief and who are at risk of poor health related outcomes (Bryant, 2012; Zisook & Shear, 2009). Grief affects immune function where the bereaved individual is more likely to suffer from

psychological and somatic health problems and be at greater risk of mortality, which is linked to grief through poor nutrition, lack of exercise, drug and/or alcohol use, as well as by suicide, particularly in the earlier bereavement period (M. Stroebe, Schut, & Stroebe, 2007). According to these authors there is evidence that psychiatric morbidity such as depression is increased, and in some cases, relationships, social activity, concentration and work performance may become compromised. Given the high morbidity and mortality rates in this minority of people, the challenge lies in identifying these individuals so that poor outcomes can be avoided, or at least minimized (Prigerson et al., 2009).

### **The Call for a Conceptual Model of Complicated Grief**

Rando (2013) is critical of the recent tendency to measure grief related distress, rather than the process of grieving. She suggests that in the complicated/prolonged grief debate there are erroneous understandings of prolonged grief disorder that detract from the complexity of complicated grief; for example the association with grief-related major depression is an impediment to building a conceptual model for complicated grief. There is therefore an urgent need to operationalize grieving to ensure debate and empirical research centre on an agreed upon construct, and so that valid assessment measures can also be developed. Rando suggests the inclusion of the following elements when developing a conceptual model: the individual nature of grief; the use of explanatory theories; underlying coping mechanisms; primary issues and current functioning of the bereaved person; the function of grief in the individual; the form grief takes, as well as the hypothesized operational course. Such a conceptual model would have a number of advantages recognizing the different features of complicated grief and also accounting for those in a subclinical group. While it is hoped that the efforts of research teams will be maintained, grief remains a highly contested issue (Knoll, 2012; Rando, 2013; Rosner, 2015), with environmental and cultural contexts often ignored (Granek & Peleg-Sagy, 2015). Given the lack of consensus on the operationalization of grief, it is worth reviewing the risk and resilience factors associated with prolonged or complicated grieving processes.

### **Risk and Resilience Factors Associated with Grieving**

Much research has been directed towards identifying both risk and resilience factors associated with poor bereavement outcomes (Relf et al., 2010; M. Stroebe et

al., 2007), with risk factors and protective factors possibly at each end of a continuum (M. Stroebe, Folkman, Hansson, & Schut, 2006). In a review of research related to the predictors of complicated grief, Lobb and colleagues (2010) identified many factors, such as for example, insecure attachment styles, dependence on the deceased, the closeness of the relationship, childhood adversity, and parents' reactions after the death of their child, to be highly predictive for complicated grief. These are only a few predictors that top a long list. Parkes (1996) grouped phenomena associated with poor bereavement outcomes as 'antecedent factors' (e.g. mental health diagnosis), 'concurrent factors' (e.g. age, religiosity), and 'subsequent factors' (e.g. social isolation). An accumulation of these features, he believed, would result in poor bereavement adaptation. W. Stroebe and Schut (2010) added 'situational factors', for example, sudden or traumatic death, and 'personal factors', such as personality traits. Given the difficulties posed by assessing grief-related distress (Rando, 2013) it is worth considering the assessment of risk and resilience factors associated with grieving.

### **Who Needs Bereavement Support?**

Only a small number of people, perhaps between 10% and 15% of the bereaved population, may have complicated or prolonged grief, and are at risk of developing longer term mental health problems, or other health related poor outcomes (M. Stroebe et al., 2007). In an Australian population based survey, Aoun and colleagues (2015) report 6.4% of bereaved people were in this risk category, and a similar survey by Kersting, Brähler, Glaesmer, and Wagner (2011) in Germany found an incidence of 6.7%. It is this minority of bereaved individuals that palliative care services should support after the death of the patient (Palliative Care Australia, 2005b); however, assessment is the first step in identifying those caregivers in need of support and, as mentioned earlier, current bereavement risk has been determined on informal, ad hoc, observational means (Payne & Relf, 1994) with blanket bereavement support provided to all caregivers regardless of need (Breen et al., 2014).

**Efficacy of bereavement support.** The provision of professional grief support to the vast majority of bereaved people is not effective for a number of reasons (Rumbold & Aoun, 2014). Firstly, most clinical interventions for bereavement have been found to be ineffective (Schut, 2010), particularly when applying treatments for

depression or PTSD to grief (Bonanno, 2006). Additionally, professional intervention soon after a loss may interfere with the natural course of the grieving process, disrupting the grieving person's ability to develop coping strategies and resulting in isolating the grieving person from his/her usual support networks (Rumbold & Aoun, 2014). Neimeyer (2000) suggests that therapeutic intervention may even be harmful when applied to those who integrate their loss in time, and therefore, the majority of bereaved people will adjust without professional assistance (Currier et al., 2008). In a quantitative review of psychotherapeutic interventions, the authors found that time did not relieve bereavement distress for those with maladaptive responses to loss. This group of bereaved were more likely to benefit from early targeted intervention. Given the inappropriateness of providing blanket bereavement intervention, attention needs to focus on the provision of support based on individual need (Breen et al., 2014).

### **Nosology of Grief: Classification Systems**

In order to move towards identifying those individuals at risk of poor health related outcomes, as well as provide clarity for further research efforts, Prigerson and colleagues (2009) developed standardized criteria for inclusion in classification systems such as the World Health Organisation's (WHO) *International Classification of Diseases* (ICD) (World Health Organisation, 2015) and the *Diagnostic and Statistical Manual of Mental Health Disorders* (DSM) (American Psychiatric Association, 2013). Although the DSM was first published in 1952, the revised third edition (American Psychiatric Association, 1987) was the first edition to mention 'uncomplicated bereavement' hinting at a link between different grief responses and existing mental health conditions (Marwit, 1991). Given the wide cultural and individual expressions of grief, concerns were raised by the DSM taskforce in relation to grief as being complicated or abnormal (Prigerson, Frank, et al., 1995). At a time when there was much debate concerning various forms of grief, such as delayed or inhibited grief, concern was raised that the DSM-III-R had not clarified the many forms of grief needed to assist clinical diagnosis; as such, there was a call for research to investigate underlying grief mechanisms (Marwit, 1991).

As discussion on nomenclature continued in the early 1990s, Horowitz, Bonanno and Holen (1993) offered criteria for 'pathological grief' for inclusion in the next edition of the *Diagnostic and Statistical Manual for Mental Health Disorders*

(DSM-IV), believing that some individuals were in need of assistance because they were failing to adapt to their loss, disrupted by symptoms such as intrusive imagery and avoidance behaviours. This situation is similar to those who meet posttraumatic stress disorder (PTSD) symptomatology. Preliminary studies by Horowitz and colleagues found that some bereaved persons met diagnostic criteria for a major depressive disorder (MDD) without comorbid diagnoses; others met criteria for both MDD and pathological grief; yet others met criteria solely for pathological grief. Following the initial bid for a pathological grief category in the DSM-IV, research has since been extensively conducted by both clinicians and researchers (Boelen & Prigerson, 2013).

The DSM-IV, published in 1994, went some way to addressing the problem of those needing treatment for co-morbid issues following the death, by allowing a diagnosis of MDD at two months post-death (Prigerson, Frank, et al., 1995). However, the focus remained on depressive symptoms rather than symptoms of grief such as preoccupied thinking about the deceased. At this time the authors referred to maladaptive grief responses as complicated grief which were shown to differ substantially from bereavement-related depression, in spite of studies showing that high numbers of bereaved participants with complicated grief also met criteria for major depression and anxiety disorder (Kim & Jacobs, 1991). Kim and Jacobs stated that separating grief from depression had important implications for treatment given antidepressant medication had been found to be ineffective in bereavement. The distinction also opened the way for reimbursement from third-party insurance providers (Prigerson, Frank, et al., 1995). The corresponding ICD-10 published in 1992 closely aligns with the DSM-IV and is current at the time of writing (Prigerson et al., 2009).

Prigerson, Maciejewski and colleagues (1995) revealed a cluster of anxiety symptoms such as restlessness, tenseness, irritability and nervousness, with another group of depressive symptoms comprising sadness, apathy and expressions of guilt. However, a third grief specific group of symptoms emerged such as preoccupation with thoughts of the deceased, yearning, searching for the deceased, and disbelief about the death. The researchers suggest that this third cluster of symptoms is a reliable predictor of dysfunction in the longer term. Research continued with others replicating these findings (Boelen, Van den Bout, & De Keijser, 2003). Evidence was mounting

that some individuals were incapacitated by complicated grief and as a result suffered cardio-vascular problems, sleep disorders, suicidal ideation, and were still at increased risk of cancer two years post-loss (Chen et al., 1999). Latham and Prigerson (2004) found that those meeting complicated grief criteria were at significantly greater risk of suicide; conclusions also reached by Ajdacic-Gross et al. (2008) who found that suicide risk was greater in early bereavement.

A revised edition of the diagnostic manual was published (DSM-IV-TR) (American Psychiatric Association, 2000) describing symptoms of bereavement as similar to Major Depressive Episode (MDE) noting the various cultural expressions of grief. The manual advised clinicians to differentiate between grief and depression, recommending the use of depressive disorder criteria should symptoms persist two months post-loss. Concerned that the DSM-IV-TR was not assisting clinicians to identify those individuals at greatest risk of poor outcomes, Prigerson, Vanderwerker, and Maciejewski (2008) proposed a new bereavement category for the fifth edition of the DSM, believing that this clinically significant syndrome met DSM guidelines as a mental disorder due to the distress caused to the individuals in question. Using the term prolonged grief disorder (PGD), the authors believed the new term would offer greater clarity for clinicians, stating that the previous earlier names such as traumatic grief is easily confused with posttraumatic stress disorder; pathological grief is a derogatory label; and complicated grief might imply difficulty in understanding, explaining, and therefore treating grief. Prolonged grief, they suggested, better described the nature of grief, although they cautioned against duration being the main indicator of the disorder. The term complicated grief (CG) is preferred by Shear and colleagues (2011) who conceptualize grief as being adversely influenced by circumstances affecting expected recovery. More recently there seems acceptance for both terms used in tandem and abbreviated PGD/CG (Boelen & Prigerson, 2013).

In a bid to have PGD included in the DSM-5 and ICD-11 Prigerson and a team of grief researchers and clinicians (Prigerson et al., 2009) established diagnostic criteria in an algorithm which seemed useful in detecting people meeting PGD criteria at six to twelve months post-loss. Shear and colleagues (2011) also developed criteria for complicated grief, showing that a diagnosis could not be met prior to six months post-loss. Other researchers and clinicians were concerned that the delineation between complicated grief and disorders such as depression had not been sufficiently clarified,

and that a grief category may lead to pathologizing all forms of grief (Breen & O'Connor, 2007; Otto, 2014; Shear et al., 2011). While the majority cautiously welcomed the addition of a category for those in need of clinical attention, others were concerned that PGD/CG was restrictive and failed to recognize the multiple forms that complicated grief could take, such as for example, delayed or traumatic grief (Rando et al., 2012). These authors called to broaden knowledge about grief, such as may occur in non-death related situations; to be sensitive to terminology used; to be culturally and spiritually sensitive; and to recognize the need for a category for individuals who warrant attention without a formal diagnosis.

The DSM-5 (American Psychiatric Association, 2013) was published in 2013; however, neither PGD nor CG was included. Rather Persistent Complex Bereavement Disorder (PCBD) has been listed in Section III as a condition for further study, and has a 12 month exclusion period following the loss before a person could potentially meet criteria for treatment. At the same time the two month bereavement exclusion was removed from Depressive Disorders which appears in Section II. This allows those with co-morbid mental health diagnoses, such as depression or anxiety, to receive assistance if warranted. The section highlights the correspondences between grief and depression, and recommends clinical judgement be used to distinguish between a normal grief reaction and depression. Section II also contains a category for “other conditions that may be a focus of clinical attention” (p.716) and stipulates that *Relational problems/Other problems related to primary support group - Uncomplicated Bereavement* may require attention due to interaction with another medical disorder (American Psychiatric Association, 2013). There is ongoing discussion about normal grief and the clinician is urged to seek further guidance on differentiating normal from depressive symptomatology before making a diagnosis in a similar way to the discussion about depressive disorders (American Psychiatric Association, 2013). There has been criticism, however, that such changes may result in grieving persons being inappropriately treated with medication or, alternatively, misdiagnosed or even not diagnosed and missing out on treatment (Rosner, 2015). In the meantime, the forthcoming version of the *International Classification of Diseases* (ICD-11) is expected to include a new category for PGD given it has its own unique symptom profile and treatment (Maercker et al., 2013). This version of the ICD is



expected to be less medically focused than previous editions, and weighted towards a behavioural viewpoint (Clay, 2012).

### **Possible Solutions to Complex Issues**

A way forward would be to apply a public health model of bereavement care so as to align need with support within a partnership of community services (Aoun, Breen, et al., 2012; Relf et al., 2010). The National Institute for Clinical Excellence (NICE) (2004) in the United Kingdom promotes a comparable model based on the bereavement needs of caregivers, recognizing that caregivers will have a range of different needs from information and/or peer-support group assistance, to formal counselling interventions. The public health model of bereavement support proposed by Aoun, Breen, O'Connor, Rumbold, and Nordstrom (2012) also advocates that palliative care services provide information about grief and bereavement, as well as how to access available support, for all bereaved people. The majority of people, approximately 60%, would be considered to be at a low level of risk and would adjust well in time with the support of family and friends. Around a third of bereaved people, considered to be at a moderate level of risk, may need some additional support such as a peer support group or volunteer-led community programme. The remaining high risk category, the approximate 10% who may have PGD/CG who are at risk of ongoing physical and mental health issues, would most likely benefit from professional specialist services.

### **Rationale for This Research Study**

**Bridging the gap.** In order to bridge the gap between the present practice of bereavement support and standards and guidelines for clinical palliative care practice (Breen et al., 2014), the development of an effective and reliable model of bereavement risk assessment would be an important first step towards effective provision of support by palliative care services. Indeed, an international study has identified bereavement research as a priority, with the development of assessment measures being recommended by over 90% of respondents (Hudson, Zordan, & Trauer, 2011). Palliative care service providers in Perth, Western Australia, have also identified bereavement risk assessment as a priority (Aoun, O'Connor, et al., 2012) and, as such, provided the impetus for this study.

**Advantages of aligning need with bereavement service support.** Adopting a public health model of bereavement support as a framework to match support with need, as discussed above, has a number of advantages (Aoun, Breen, et al., 2012). The model accords with recommendations by bereavement standards (Hall et al., 2012) in addressing the complexity of individuals' differing needs, and would address existing palliative care service barriers such as funding and service provision (Agnew et al., 2011; Field et al., 2007). It is anticipated that by categorising need, referral pathways to support services, (both within the palliative care service and to external services) can be developed (Palliative Care Australia, 2005a). Support for the viability of the public health model's ability to align need with support has recently been demonstrated with a population survey (Aoun, Breen, et al., 2015) and is an appropriate fit for this research.

**Taking advantage of the patient's pre-death window of opportunity.** Palliative care services are ideally placed in that they provide an opportunity to assess caregivers' risk of poor bereavement related outcomes, so as to offer timely support if necessary (Agnew et al., 2010). However, an assessment model would need to be acceptable, feasible for use and sustainable for ongoing practice by palliative care services, and as such, would best be developed in collaboration with palliative care stakeholders by the use of action research methodology (Froggatt, Heimerl, & Hockley, 2012). This collaborative approach empowers palliative care stakeholders, as both participants and collaborators, to bring about change in practice that will be feasible, practicable and sustainable in the clinical setting, and to lead to wider change at an organisational and community level.

**Parsimonious use of resources.** To develop a bereavement risk assessment model which reliably matches need with the provision of support should also result in more economical use of valuable palliative care resources (Breen et al., 2014). Given the link between lack of psychological support during the caregiving trajectory and poorer mental health outcomes following the death of the patient, a streamlined assessment protocol based on caregiver self-report should provide caregivers with an avenue to voice their concerns as a matter of routine with the provision of timely and appropriate support if needed (Aoun, Grande, et al., 2015). It could reasonably be expected that appropriate and timely intervention might prevent the development of

complicated grief reactions later in the bereavement trajectory (Boerner, Mancini, & Bonanno, 2013).

**Person-centred care.** The development of a model using a caregiver self-report measure in place of staff observations would also move towards person-centred care (McCormack & McCance, 2006). As mentioned in Chapter One, person-centred care accords with Australian *National Safety and Quality Health Service Standards* (Standard Two - Partnering with Consumers) which recognizes the role of caregivers in decision-making and treatment planning. The flow-on effects of improved health outcomes in terms of decreased mortality, reduced hospital admissions and readmissions, lower economic costs and increased health worker satisfaction is the ultimate goal of partnering with patients and their caregivers (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011).

**Benefits to palliative care staff.** A comprehensive caregiver self-report assessment would also provide staff with more reassurance and certainty that caregivers have an avenue to express their concerns so that their needs can be addressed routinely as needed. The recent introduction of a Carer Support Needs Assessment Tool (CSNAT) in a community palliative care service has been well received by nurses, because it has allowed staff to focus on their primary goal of care; care of the dying patient (Aoun, Toye, et al., 2015). The nurses also found the tool gave guidance to the previously informal, unstructured chats; created more understanding and closeness with the caregivers; identified needs that would not have otherwise been identified; and challenged staff intuition about the caregivers who they had deemed strong who reported they were not coping when assessed directly. Research shows that when an individual's needs are given attention, as in a person-centred approach, benefits accrue not only to the individual family caregiver, but there is also increased job satisfaction for staff (Ross, Tod, & Clarke, 2015).

**Streamlining assessment and uniformity of practice across services.** It is also anticipated that a bereavement risk assessment model will streamline the present informal process of assessment (Agnew et al., 2011). A standardized assessment applied to all caregivers would surely provide more consistency to assessment as well as save time. Such a protocol could also be implemented across services, again providing greater uniformity to practice. The implementation of a standardized

bereavement risk assessment protocol would also bring services in line with national standards and policies. Compliance will remove the threat of ongoing funding cuts for those services not conforming to evidence-based practice (Palliative Care Australia, 2005a).

## **Conclusion**

This chapter has outlined the many issues affecting the provision of bereavement support to caregivers caring for a patient under the care of a palliative care service, particularly in relation to risk assessment and identification of bereavement support needs. A lack of clarity in relation to understanding and defining grief by clinicians and researchers, creates problems in the assessment of grief responses (Rando, 2013) and has been discussed at length, particularly in relation to diagnostic nomenclature. The present clinical practice issues have been discussed and highlight the extent of the gap between guidelines and standards recommendations, and the day to day practice of bereavement assessment and support by palliative care services. At present, blanket support is provided to all caregivers, with informal assessment of need based largely on staff observation and intuition (Breen et al., 2014). At best, the provision of support services to all bereaved is wasteful of resources; at worst, it may be harmful to the vast majority who adapt to their loss in time with the support of family and friends (Rumbold & Aoun, 2014). However, those at risk of high mortality and high morbidity, and those in the moderate-risk group, will possibly require professional mental health services or the additional support of counselling or peer-support groups, and it is this group in need of identification, so that palliative care services may provide appropriate and timely support if necessary (Breen, Aoun, Rumbold et al., 2015), and thus minimize the impact of future adverse health outcomes (M. Stroebe et al., 2007).

## **CHAPTER THREE**

### **Research Methodology**

“...if we want more evidenced-based practice, we need more practice-based evidence” (Green, 2008, p. 23).

#### **Chapter Overview**

This chapter describes the research methodology for the development of a bereavement risk assessment model for palliative care in Western Australia. The chapter begins with the original research aims and objectives then the overarching action research methodology is described in detail. The underlying epistemological assumptions and philosophical perspectives in relation to action research methodology are discussed. The various typologies of action research are outlined, along with an explanation of action research as a process. This is followed by a step-by-step description of the phases of the study, with an explanation of where and why the planned study deviated from the actual study in response to stakeholder input. Procedures and data analysis for each of the phases are described briefly, as they are reported in detail in subsequent chapters. The chapter concludes with ethical considerations in relation to the study generally, and specifically in relation to the added complexity of action research and palliative care. Reflexivity is also discussed with examples of how it was important in re-directing energy and focus when needed.

#### **Research Aims and Objectives**

The overall aim of the study was to develop a bereavement risk assessment model, designed to interface with palliative service providers' bereavement service protocol.

The specific objectives of the study were:

- To conduct a scoping review of the literature to identify psychometrically-sound existing bereavement risk assessment measures, feasible for use in palliative care in accordance with standards and policy, and based on a three-tiered public health model of bereavement care.

- To examine the issues related to bereavement risk assessment for caregivers who access palliative care from the perspectives of relevant stakeholders.
- To identify barriers to, and facilitators of, change within the background of organisational culture in three models of service provision: namely a palliative care unit (PCU) located within an acute hospital; a palliative care consultative team operating in a major tertiary teaching hospital; and a community based palliative care service providing domiciliary care.
- To engender lasting change in practice by palliative care health care professionals in the context of their organisational culture and values, so as to ensure improved service provision, leading to improved mental and physical health for those at risk of poor bereavement outcomes.

## **Research Design**

The overarching methodological approach for this study was action research. Increasingly, action research is used in the health field, where researchers work collaboratively with health professionals and policy makers, taking a bottom-up approach, and where the research process itself facilitates change in practice (Baum, MacDougall, & Smith, 2006). Action research is regarded as “research about practice” (Stringer & Genat, 2004, p. 32); its central rationale to generate knowledge that is practical and useful in daily life which ultimately results in new ways of understanding (Reason & Bradbury, 2001a). Action research originally aimed to bridge gaps between research, theory and practice (Holter & Schwartz-Barcott, 1993), and to do so by observing scientific principles (Friedman, 2001). It is an ideal framework for this research given, as Reason and Bradbury state it usually begins with a question as to how any given situation may be improved. Indeed, action research questions are typically derived from practitioners in specific practice settings (Argyris & Schon, 1989) and ideally action research would be initiated at the request of practitioners (Kidd & Kral, 2005).

As outlined in Chapter Two, problems with the provision of bereavement support have been identified (Field et al., 2004) and Western Australian palliative care service providers and health professionals have expressed dissatisfaction with current bereavement risk assessment practice and have voiced their readiness for change

(Aoun, O'Connor, et al., 2012). Action research engages such health professionals as both collaborators and participants, thus enabling them to take action, building change from within their organisations via a cyclical process of gathering information, analysing the information, taking action, and again reflecting on, and evaluating the outcome of the action taken. In this way reflection and action are inseparable. This iterative process is continued until such time as the research problem is resolved or the desired change in practice occurs (Baum et al., 2006).

### **What is Action Research?**

There is no one clear definition of action research due largely to the numerous approaches based on their philosophical perspectives, which are reflected in the many terms used; participatory research; critical action research; appreciative inquiry; action inquiry; cooperative enquiry; first person enquiry; action science; community action research and new paradigm research (Hockley et al., 2013). Action research may also be classified according to the research methods employed, research topic, or level of participation by stakeholders (Waterman, Tillen, Dickson, & De Koning, 2001) and may be more readily conceptualised as a family of approaches concerned with a range of assumptions (Reason & Bradbury, 2001b). In light of such variance, Reason and Bradbury (2001a) offer the following description:

Action research is a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview which we believe is emerging at this historical moment. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities (p.1).

### **Features of Action Research**

Action research has seven distinguishing features. It comprises individuals within groups (the participants) who are the subject of the research, but who are engaged and invested in the research and its solutions. It is therefore collaborative by nature. Central to action research is the identification of a problem, or problems, within organizations, workplaces, settings or communities. It is future-focused in that it

involves interventions or actions by the participants/researchers, and ultimately leads to enhanced understanding that may generate new knowledge resulting in improved practice or change in some way; as such, action research is also educative (Hart & Bond, 1995). For example, such projects would include those that develop palliative care practices in care facilities, where the emphasis may be on introducing advance care planning, or projects that focus on groups such as those with disability or dementia (Froggatt et al., 2012). Waterman, Tillen, Dickson, and de Koning (2001) add that action research is context-specific and dynamic, often an iterative process of problem identification, collective reflection on the problem, action-planning, action-taking, and evaluation. In a systematic review of the literature, the authors conclude that the most distinctive essential features common to action research are the cyclic activity that often involves a change intervention, and the active involvement of participants in overcoming the research problem.

### **Philosophical Underpinnings of Action Research**

There is much debate concerning philosophical paradigms, terms and definitions of action research. According to Waterman and colleagues (2001) the collaborative nature of action research aligns with a critical theory philosophical viewpoint where voice is given to those who are affected by the research question. Critical theory resulted from questioning the role of positivist science and its relationship with research as being non-democratic and elite. In action research participation by the researched as collaborators is a central tenet (Waterman et al., 2001).

In contrast to a positivist approach, action research from a critical theory viewpoint recognizes that there are multiple ways of knowing, and that knowledge of theory is not deemed superior to knowledge of practice. Practice in the clinical setting is examined by clinicians within the services using a bottom-up approach, rather than having knowledge applied from external researchers or management as a top-down strategy which may be out of touch with clinical practice (Hockley et al., 2013; Waterman et al., 2001). Indeed, so-called objective research methods that have been conducted by researchers removed from the organisation, workplace, or community under study, have sometimes been criticised for their failure to deal with the complexity of problems within a given context (Waterman et al., 2001). The stringent



scientific conventions that produce theories under controlled conditions can be difficult to apply to the changeable world of clinical practice (Friedman, 2001). Friedman suggests that action science practitioners would question the relevance of positivist science theories in the day to day practicalities in the world of organisations, where results of statistical analyses for example, should not predominate; rather, the individuals within the setting or organization with their various forms of knowledge should have primacy.

Froggatt, Heimerl, and Hockley (2012) suggest a synergism between action research and palliative care given both disciplines have resulted from limitations imposed by dominant research approaches (in the case of action research), and care for those who are dying (in palliative care). Both action research and palliative care are relative newcomers to the disciplines of research and healthcare, and both are becoming increasingly prominent. The authors believe that both action research and palliative care have a 'holistic dynamic' in that the individual and his/her needs are located within a greater social network; in action research the individual is situated within the community or stakeholder group; in palliative care the individual is located within a network of community of friends and family. Using action research methodology in palliative care can be challenging due to the participatory nature of action research and the demanding nature of palliative care that the research serves. However, as Friedman (2001) states, when people can discover for themselves where problems arise in their own practice or community, they are in a better position to effect the change required.

### **Types of Action Research**

Given the lack of consensus in relation to defining action research, Hart and Bond (1995) have proposed that in health care there are four typologies of action research spanning a continuum with a consensus model of society on one end, and a conflict model of society on the other. The four types are: the experimental type, where resolution of the problem is attempted according to the research aims; the organizational type, where the problem is aimed to be solved in accordance with management's aims; the professionalizing type, where resolution is sought in accordance with the best interest of the professional group; and finally the empowering type which seeks to resolve the problem via the process of change and the

understanding generated through the process. Different types may be salient at different stages of any action research project. The present study aligns most closely with Hart and Bond's professionalizing type, where the research problem emerges from professional practice and is defined by the professional group, with resolution of the problem in the interests of research-based practice and enhanced professionalization of the service. The professional group membership comprises interdisciplinary professionals and service consumers, in the case of the present study palliative care health professionals and caregivers caring for a significant other with life-limiting illness. Furthermore, the change intervention is pre-defined and processed, as in the present study where bereavement risk assessment specifically had been identified by the stakeholder community to be in need of revision. According to Hart and Bond, the research and action components are in tension with research often taking precedence. In the case of the present study, and as discussed in Chapter Two, research has shown the gaps between policy and practice (Breen et al., 2014), where the present practice of bereavement assessment continues to be less than optimal in leading to good outcomes for bereaved individuals (Agnew et al., 2011).

Other typologies of action research have been categorized and described by Holter and Schwartz-Barcott (1993) who suggest there are three main approaches: a technical collaborative approach; a mutual collaboration approach; and an enhancement approach. While not all action research involves an intervention (Waterman et al., 2001), the goal of a technical collaborative approach is to apply an intervention based on a theoretical framework to the identified problem situated in a clinical setting; as such it is predictive and deductive (Hart & Bond, 1995). Interaction between the researcher and practitioners is based on mutual agreement in facilitating help with implementation of the intervention and generally results in early and efficient change in practice. The other two approaches are more focused on a collaborative exploration of the problem, its causes and possible solutions, with the potential need to raise collective awareness of the problem before an intervention can be planned (Holter & Schwartz-Barcott, 1993). This study aligns more closely with the technical collaborative approach described by the authors.

## **Action Research as a Process**

As a process action research entails observation and/or diagnosis, reflection and planning action, taking action, and evaluation of the action taken in any individual cycle with outcomes from the previous cycle informing the next cycle (Hockley et al., 2013). It is possible that information gleaned during a cycle may be in itself an agent of change which may negate the need of further action cycles (Waterman et al., 2001). The need for examining bereavement risk assessment practice had already been identified by local palliative care service providers (Aoun, O'Connor, et al., 2012), and had been reflected in national and international literature (Hudson, Zordan et al., 2011).

**Reflection and planning.** At the outset, the focus of the enquiry must be clearly apparent in order to progress in the required direction (Hart & Bond, 1995). The enquiry in this case is primarily focused on the practice of bereavement risk assessment by palliative care health professionals and, as such, views and opinions of this group will be elicited throughout the study along with some input from bereaved former caregivers and those presently caring for a patient in palliative care, given the resulting practice will need to be compatible with caregiver needs.

**Action.** The nature of action research as a practical application to problems involving collaboration with stakeholders and the use of various methods is an active process of change. Such a process leads to change at multiple levels from the individual, through teams and groups and the organization itself, to potentially having a broader effect on policy and practice (Froggatt et al., 2012). Action/s taken regarding the problem in question result from participants' enquiries and reflections and provides new ways of viewing practice and also has the potential for new ideas and new directions (McIntyre, 2008). As McIntyre (2008) states, new ideas generated from the enquiry or action resists linear ways of working with the problem, and may lead to yet more lines of enquiry or changing goals.

**Evaluation.** Evaluation is an essential element to action research because of its importance in informing the outcome of an intervention, and is influential in the direction the research takes. It is generally the participants who evaluate the relevance that the research process and its outcomes may have (Khanlou & Peter, 2005). According to Froggatt and Hockley (2011) the purpose of evaluation may have several

goals; it may describe the intervention; it may assess the consequences of the intervention thus enabling a decision to be made about the intervention; or it may provide insight into the consequences of the intervention. Evaluation therefore must be undertaken systematically with information gathered prior to, and after a course of action in order to make trustworthy comparisons. There are numerous methods of evaluation and the method chosen should be compatible with the research aims and epistemological foundations. Such methods may be naturalistic or positivist, and often involve the use of surveys, questionnaires or interviews and their usual means of evaluation (Frogatt & Hockley, 2011). Apart from determining that a goal has been reached, or that a new cycle should be commenced, evaluation may result in the discovery of new problems that may necessitate a new cycle of reflection, action and evaluation. It is also possible that the action itself is knowledge that aids understanding, and thus becomes an agent for change or improved practice (Waterman et al., 2001).

### **Action Research: Participants and Participation**

Action research participants include individuals as partners with the researchers. This partnership necessitates the individual to reflect on his or her own part in the collective understanding and contribution to the research problem and the solution (Waterman et al., 2001). Without this critical reflection it is unlikely that change in practice will occur (Hockley et al., 2013). In this respect, action research is empowering both individually and collectively.

In action research, the degree of participation by the stakeholder group is on a continuum ranging from co-operation with an outside researcher whom participants allow to shape the action process, to the stakeholder group itself taking greater collective ownership and driving the action of the research problem and its solutions. The degree of participation may be influenced by a number of factors: the aim of the research; the phase of the research study; the experience of the action researchers; the philosophical underpinnings of the research, and the availability of resources for the project. Different types and levels of participation may also progress simultaneously, with no one mode of participation being superior to another (Waterman et al., 2001).

A salient point is made by McIntyre (2008) who states that the most important aspect of participation is the quality of participant engagement in the research, rather

than the degree to which they participate. If participants engage in taking responsibility in the joint research, there is more likelihood that they will be committed to the process of action, change and evaluation, and will be less likely to view their participation as an obligation. The participatory aspect of action research is not only fundamental to the generation of knowledge and resulting change in practice, but is also important as a tool for inclusive, democratic research, rather than action by a group of researchers who may be located outside the action sphere (Waterman et al., 2001).

### **Planning and Preliminary Phase of the Study**

An initial perusal of the grief and bereavement literature, conducted early in the planning stage, identified a large number of bereavement risk assessment measures. As a result, an in-depth scoping review was planned for phase one to systematically catalogue instruments in accordance with the public health model of bereavement support (Aoun, Breen, et al., 2012) and the bereavement support standards (Hall et al., 2012).

Preliminary informal discussions with five local service providers were undertaken to garner interest from staff and management in relation to participating in the various phases of the intended study. Expressions of interest were sought for participation in the reference group, and for those services willing to engage in the new bereavement risk assessment model by piloting the bereavement risk assessment model with caregivers and engaging in evaluation of the risk assessment model following the pilot. The discussions with service providers occurred throughout a six month period through face to face meetings with service management and multidisciplinary team members, while telephone conversations were had with key personnel, and email follow-up at other times. Field notes were made throughout the meetings to record information about the palliative care services and their operational issues. Plans were made at this time to establish a reference group of health professionals and bereaved former caregivers to develop the assessment model. A commitment to participate in piloting the bereavement risk assessment model and evaluating the model was also made by three local palliative care services at this time.

## **Action Cycles: The Planned Study**

While an action intervention may be established at the outset of a research study, the planned intervention must be responsive to input from the stakeholder group and be amenable to change, if the change in practice is to be successful (Froggatt et al., 2012). As the primary aim was to develop a bereavement risk assessment model for use in palliative care as identified by local service providers (Aoun, O'Connor, et al., 2012), a number of phases were planned at the beginning of this study to achieve this goal:

- Phase one (Chapter Four) of the initial action research study was to identify existing grief measures, via a scoping review of the grief and bereavement literature, for presentation to the palliative care stakeholder group in phase two. The objectives of the review were to identify existing grief measures, evaluate the measures' psychometric properties, and evaluate their applicability and feasibility for use in palliative care clinical settings (Sealey, Breen, et al., 2015). It was anticipated that existing grief measures would be used to develop the model in accordance with bereavement support standards (Hall et al., 2012) as discussed in Chapter Two.
- Phase two (Chapter Five) of the study comprised a reference group of palliative care health professionals and a bereaved former caregiver. Information was gathered on what participants viewed as necessary attributes of a bereavement risk assessment protocol. Grief measures identified in the scoping review (phase one) were presented to the reference group in order to develop a bereavement risk assessment model that would be feasible for use in clinical practice. The reference group also discussed issues related to bereavement risk assessment practice, identifying barriers to, and facilitators of change to present practice (Sealey, O'Connor, Aoun, et al., 2015).
- Phase three of the planned study was to trial the bereavement risk assessment model, developed by the reference group in phase two, on caregivers at three palliative care services. As the model was intended to be compatible with bereavement standards (Hall et al., 2012) the grief measures would have been used to assess caregiver grief at three points in time; from prior to the patient's death; in the short period following the patient's death; and at approximately

six months following the patient's death. Three local palliative care services representing three models of palliative care service provision had expressed a willingness to participate in the study during the preliminary stages. Prior to the trial of the model on caregivers, intentions were to conduct preliminary consultations with staff at each of the participating palliative care sites so that the assessment protocol would be compatible with their work processes.

- Phase four was to evaluate the bereavement risk assessment model on the bereaved former caregivers who had participated in the phase three trial of the model. It was intended that evaluation would be conducted via semi-structured one-on-one interviews with bereaved former caregivers who had expressed interest from invitations extended during the trial period.
- Phase five was to evaluate the bereavement risk assessment model's application to clinical practice and feasibility of use with palliative care health professionals, staff members and management at the participating sites. Evaluation was to be conducted via small focus groups, or one-on-one semi-structured interviews, depending on staff preference and work schedules. Evaluation was also intended to be conducted on management at the three participating palliative care services via semi-structured one-on-one interviews. While establishing the efficacy of an intervention is important, it gives little idea of its fit in the under-resourced world of health settings (Glasgow, Vogt, & Boles, 1999), and feasibility of using a bereavement risk assessment model was a major objective of the present study.
- Finally, a summary of findings and recommendations would be collated and distributed to palliative care key stakeholders.

### **Responding to Action Research: The Actual Study**

While the study had been carefully planned as outlined above, in keeping with action research principles, the direction of the study and subsequent phases undertaken were influenced and guided by the participants through reflection of information on the issues during earlier stages of the study (Hart & Bond, 1995). The preliminary phase of consulting with stakeholders and preparation for the study, the scoping review of the literature and collaboration with the reference group (phases one and two respectively) were conducted as planned along with the final evaluation (phase five) and

dissemination of information phases. However, building on findings from phases one and two (scoping review of the literature and reference group collaboration respectively), phases three and four were altered due to the need to develop a new brief grief measure suitable for palliative care.

- Phase three of the modified study (as described in Chapter Six) was the development of a new brief grief measure across five steps; identification of predictors and risk factors for complicated or prolonged grief; construction of a pool of items for use in the measure; collaboration with an advisory group of bereavement service providers and bereaved former caregivers to select items for the measure; revision of the items on the measure by an academic team; and pilot of the measure at three palliative care services.
- Phase four (Chapter Six) piloted the new measure with caregivers presently caring for a patient in the three palliative care services. However, the grief assessment was administered to caregivers presently caring for a patient in a palliative care service, prior to the patient's death, and not at the two post-death points as originally planned.
- Phase five (Chapter Seven) evaluated the new grief measure as per the original plan, with the staff and management at the participating palliative care services. The evaluations were accomplished via focus group discussion and one-on-one interviews.

**Summary of findings and recommendations.** A key characteristic of action research is that it is educative (Hart & Bond, 1995). Through stakeholder participation in the dynamic cyclic approach of action research, problem identification, action, and evaluation are linked and, as a result, new knowledge and understandings are generated. The knowledge may be theoretical or practical and applicable, empowering stakeholders in bringing about new ways of understanding or alternative ways of working in practice (Waterman et al., 2001). In keeping with the philosophical roots of action research it is important that the knowledge generated during the action phases has the opportunity to influence future practice by being distributed to the wider palliative care community. Following analysis of the evaluation data, findings and a summary of the research were given to the participants in the study: the health professionals; bereaved former caregivers; and caregivers who requested the



information during the consent process. A summary of findings and recommendations was collated for dissemination to all local palliative care service providers and various stakeholder organizations. The study's outcomes have also been presented locally at an annual palliative care study day for health professionals, at a national palliative care conference (Sealey, O'Connor, Breen, & Aoun, 2015) and grief and bereavement conference (Sealey, O'Connor, Breen, & Aoun, 2014b) as well as at an international grief and bereavement conference (Sealey, O'Connor, Breen, & Aoun, 2014a).

### **Procedures Throughout the Phases of the Study**

Because action research is context-specific, a number of qualitative or quantitative methods may be employed through the various action cycles to achieve the study's goals; as such, the analysis of research data will also vary accordingly (McIntyre, 2008). The present study used qualitative focus group methods and one-on-one semi-structured interviews. Full details of the procedures in each of the phases of the study have been discussed in the relevant chapters; however, a brief overview follows.

**Reference group of key palliative care stakeholders.** Eight palliative care health professionals and one bereaved former caregiver (n=9) were recruited from various local services representing a range of models of service provision, as well as professional job designations representative of a typical palliative care multidisciplinary team (phase two). Purposive sampling was used to ensure a broad mix of job disciplines were represented in the group. Three separate 90 minute meetings were held with the same group members over a five week period to examine issues relating to bereavement risk assessment in practice and to develop a bereavement risk assessment model for use in clinical practice.

**Advisory panel of stakeholders.** Six bereavement service providers, including counsellors, psychologists, and social workers were recruited from palliative care services and private practice, along with two bereaved former caregivers (n=8). One-on-one, low-structured interviews, (so as not to restrict the participants' responses), were conducted iteratively over a three month period for the development of the measure (phase three).

**Pilot of new measure on caregivers.** Nineteen caregivers were recruited across the three participating palliative care sites (phase four). The caregivers were adults over the age of 18 who were caring for a loved one, family member, or friend with life-limiting illness. Staff at the consultative service recruited caregivers they considered suitable to engage in the assessment and administered the assessment, staff at the community service recruited two caregivers they deemed suitable to assess, while I recruited three caregivers at the in-patient unit. I also administered the assessment to these five caregivers at these two services. The assessment consisted of a pen and paper grief self-report measure and feedback form to ascertain acceptability of using the measure. The feedback form also captured demographic information.

**Evaluation of the grief measure.** Two of the palliative care services participated in the evaluation phase (phase five). Four palliative care health professionals were recruited from the in-patient unit using purposive sampling to participate in the single focus group. The clinical nurse manager of the consultative service engaged in a one-on-one interview. Both evaluations used a semi-structured interview process.

In summary, the majority of data were gathered through group discussions and at times one-on-one interviews. Interviews necessitate dialogue and interaction between participants; indeed, they are reliant on such interaction, and result in a rich flow of information thus generating useful empirical data (Holstein & Gubrium, 1999). Semi-structured interviews allow participants greater latitude in responses and are more likely to facilitate the emergence of spontaneous information and unanticipated directions in the dialogue to develop, while low-structured interviews are the optimal choice to encourage participants to respond without being restricted by the researcher's questioning (Hesse-Biber & Leavy, 2011). All meetings and interviews were digitally recorded.

## **Data Analysis**

Data gathered from these discussions were analysed using a six-phase inductive, 'bottom-up' semantic analysis of information in accordance with Braun and Clarke's (2006) thematic analysis which distinguishes data related to the research questions and research problems. Data gathered from the pilot of the caregiver self-report measure in phase four were analysed using a hybrid quantitative/qualitative

content analysis approach (Hesse-Biber & Leavy, 2011) Analysis of data is described fully in each of the chapters detailing the various phases of the study: Scoping review analysis (Chapter Four); reference group meetings (Chapter Five); developing the new measure with the advisory group (Chapter Six); piloting and evaluating the measure with caregivers (Chapter Six); evaluation of the measure with palliative care health professionals (Chapter Seven).

Action research was used across the study with different participants, focusing on different tasks throughout each of the various phases and, as such; it was an iterative, dynamic process which incorporated developing relationships with participants (Rowan, 2001); exchanging ideas; gathering, synthesising and summarising, applying and disseminating the information throughout the study (Alley, Jackson, & Shakya, 2015). The researcher plays an active role in determining meaning and given the collaborative nature of action research, the health professionals and I were collaborators with opinions and agendas that have the potential to influence findings. There is potential for blurred boundaries between the researcher and the community with which he or she is working; implicated in this is the researcher's outcome expectations balanced against those of the stakeholder community (Lincoln, 2001). Action research principles hold that stakeholders' voices must be central in the decision-making process and, as such, the researcher needs to be vigilant about avoiding such blurred boundaries. Navigating between drawing knowledge from the participants during the research process, and imposing knowledge on the participants as the principal researcher, while at the same time maintaining a critical stance, was necessary (Kidd & Kral, 2005).

**Reflexivity.** As a process, reflexivity assists researchers to scrutinize how his/her assumptions and values influence the research outcomes (Alley et al., 2015). Given the well-known difficulties for researchers to remain aloof from research activities without influencing it in any way, I commenced a reflexive journal at the outset of the study (Willig, 2008). In this I recorded my feelings and ideas about the research process. Having a background of palliative care clinical practice, I as the researcher had an insider perspective which can be useful in understanding the research problem; however, because of this I also needed to constantly question my own values and assumptions throughout the research process (Alley et al., 2015).

## **Ethics Approvals**

All participants in each of the phases of the study were adults and all gave informed written consent to participate in the study. Central to research ethics are tenets holding that consent should be informed, confidentiality should be strictly maintained, and that harm to participants should be avoided (McLeod, 1996). This research was conducted in accordance with the National Health and Medical Research Council's (2007) national statement. Applications to Human Research Ethics Committees (HREC) were lodged with Royal Perth Hospital's HREC to trial the bereavement risk assessment model on caregivers at the consultancy service Approval (EC2012/167) was granted in December 2012. An application was lodged early in 2013 with the South Metropolitan Health Service HREC to trial the assessment model on caregivers at the community palliative care service (Approval number R/13/17). Following that approval, Curtin University HREC also approved the study (Approval HR30/2013; Refer to Appendix B for HREC approvals). The third palliative care in-patient service participating in the trial of the assessment model was a non-government organisation and did not have an internal HREC procedure. Management at this site required HREC approval from one of the government teaching hospitals above, and discussed the application and approved the research protocol at a meeting of their hospital board.

Action research presents greater complexity to ethical issues than generally occurs in empirical quantitative studies (Rowan, 2001). Because action research is process-led, cyclical and changeable in response to knowledge gathered and action taken (Hart & Bond, 1995), it is difficult for the researcher to anticipate at the outset of the study what will emerge from the research, particularly in relation to future directions the study may take (McLeod, 1996). The present study was no exception and HREC amendments from all three ethics committees were required on two occasions during the course of the study, when the original research plan was altered.

## **Ethical Considerations**

Conducting research in palliative care has always been a sensitive issue, due to the vulnerability of this population (Bellamy, Gott, & Frey, 2011). The authors suggest that concerns centre on the high emotional burden experienced by people dealing with end-of-life, and whether or not research can be justified in such circumstances. Other

concerns relate to clients having little choice but to use palliative care services, and who may fear being disadvantaged if they do not participate. However, Bellamy, Gott and Frey state (2011) that palliative care clients often welcome the opportunity to participate in research. Reasons most cited include: being of benefit to others in the future; helping improve present services; a desire to leave a legacy, or give something back. Some reported feeling empowered and valued, especially at a time when their usual social identity was under threat by the illness (Bellamy et al., 2011). Other research shows that bereaved people find it helpful, rather than painful, to have the opportunity to reflect on their experiences (Bentley et al., 2014; Payne & Field, 2004).

**Informed Consent.** Participants in this study have comprised various groups in varying numbers at each of the phases. The reference group participants in phase two were palliative health care professionals from three metropolitan settings, and a bereaved former caregiver. The advisory group participants in phase three were bereavement service providers, such as psychologists, counsellors and social workers, as well as two bereaved former caregivers. Phase four participants were adult caregivers, presently caring for a patient in a palliative care service, while palliative care health professionals were participants in the evaluation phase. All participants, whether caregivers or health professionals, were given detailed information on the overall study, as well as information on the specific phase they were taking part in, both written and verbal formats, prior to participation. This information was detailed in a five page participant information and consent document as required by the health sites HREC protocols. (Refer Appendix C for caregiver participant information and consent form).

All participants were encouraged to ask questions and caregiver participants were additionally advised to discuss their decision to participate in the study with a friend or relative before making a final decision. The information document also outlined the potential benefits and risks of participating. It was made clear that consent would be voluntary, and participants were able to withdraw from any of the groups or research procedures at any time. Caregivers were reassured that the research process was separate from the medical service, and that by not participating in the research, or deciding to withdraw after commencing the process, would not compromise the patient's care in any way, at the time of the study or in the future. All participants who

took part in the study signed a consent form, and for those undergoing an interview, consent was required for recording the interview.

**Beneficence.** The benefits to this research were deemed to outweigh the risk to bereaved caregivers (National Health and Medical Research Council, 2007). It was anticipated that the benefits to caregivers would result in improved identification of their support needs following the deaths of their family members or loved ones, so that more timely and appropriate support could be provided, than is currently available in practice.

**Privacy and confidentiality.** The privacy of participants' data was protected by allocating identification numbers to ensure anonymity beyond the researcher was preserved. No unnecessary demographic information was retained. Publications relating to the study have not included identifying information, with demographic information about participants presented as means rather than as individual data. Any future publications will likewise not identify any participants.

**Data storage and handling.** Data were stored electronically on Curtin University's secured server. Paper records, such as consent forms, completed self-report measure and feedback forms were stored separately in the researcher's allocated locked filing cabinet at Curtin University. Information will be retained for seven years on the university's secure research data storage drive before being destroyed. Only the supervisory team for this study have accessed the data (National Health and Medical Research Council, 2007).

## **Conclusion**

This chapter has outlined the research aims and objectives of the present study. The rationale for the use of action research as an overarching methodology has been explained as the best fit for this type of research study, which attempts to bridge theory, policy and practice. Action research has been described along with its underpinning philosophical foundation. The study has been described, its various phases outlined, with a brief overview of the methods used and analysis of data in each case. Detailed discussion of the methods, procedures and data analysis however, is in each of the chapters to follow: collaboration with the reference group to develop an assessment model is examined in Chapter Five; the development of a new grief

measure and its pilot on caregivers has been considered in Chapter Six; the assessment model was evaluated by palliative care health professionals and is reviewed in Chapter Seven. This chapter concludes with a discussion on the ethical considerations in general, and to those specifically relating to palliative care and action research. The following chapter (Chapter Four) gives a detailed analysis of the scoping review of the grief and bereavement literature to identify grief measures.





## CHAPTER FOUR

### Scoping Review of the Literature

“Research is to see what everybody else has seen, and to think what nobody else has thought.”  
- Albert Szent-Gyorgyi

#### Chapter Overview

Chapter Four details information gathered at the commencement of the first action phase; a scoping review of the literature, systematically undertaken to identify existing psychometrically sound grief and bereavement measures for possible use in developing a bereavement risk assessment model for palliative care. The literature review is a published review article, titled “A scoping review of bereavement risk assessment measures: Implications for palliative care,” published in *Palliative Medicine*, a peer-reviewed journal for palliative care clinicians. A detailed description of the method used in the review is given. The paper gives a detailed analysis of the 19 measures, categorised for use at three points in time; before the patient’s death, in the weeks following the death, and finally to detect prolonged or complicated grief six months or longer post-death. The review provided the necessary data which were central in the endeavour to develop a bereavement risk assessment model in collaboration with palliative care health professionals and a bereaved former caregiver in the next step of the action phase.

# A scoping review of bereavement risk assessment measures: Implications for palliative care

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1–13  
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## Abstract

**Background:** Palliative care standards and policies recommend that bereavement support be provided to family caregivers, yet uncertainty surrounds whether support currently offered by palliative care services throughout developed countries meets caregiver needs. The public health model of bereavement support, which aligns bereavement support needs with intervention, may address this gap between policy and practice.

**Aim:** The aim was to review the literature to identify bereavement risk assessment measures appropriate for different points in the caring and bereavement trajectories, evaluate their psychometric properties and assess feasibility for use in palliative care.

**Design:** A scoping review was systematically undertaken following Arksey and O'Malley's methodological framework.

**Data sources:** PsycINFO, CINAHL, PubMed and Cochrane Reviews databases, as well as grey literature including Internet searches of Google, World Health Organization, CareSearch, the Grey Literature Report and OAlster were searched. Bereavement organisations and palliative care websites, reference lists in obtained articles and grief and bereavement handbooks were also scrutinised.

**Results:** Of 3142 records screened, 356 records yielded 70 grief measures. In all, 19 measures published between 1982 and 2014 were identified for inclusion in this review, and categorised for use with family caregivers at three points in time – before the patient's death ( $n = 5$ ), in the period following the death ( $n = 10$ ) and for screening of prolonged or complex grief ( $n = 4$ ). The majority had acceptable psychometric properties; feasibility for use in palliative care varied substantially.

**Conclusion:** This review is an important preliminary step in improving the assessment of bereavement risk and, consequently, better bereavement outcomes for palliative care family caregivers.

## Keywords

Palliative care, bereavement, risk assessment, measures, instruments, family caregivers

### What is already known about the topic?

- Improving bereavement care practices in palliative care is a high priority.
- The public health model of bereavement support aligns interventions with need across three groups – the bereaved population (universal), 'at risk' group (selective) and those with signs or symptoms of a disorder (indicated).

### What this paper adds?

- This is the first review to systematically identify existing bereavement risk measures for their use at three points in the caring and bereavement trajectories, evaluate their psychometric properties and assess their feasibility for use in palliative care.
- The majority of measures exhibit acceptable psychometric properties, but their suitability for use in palliative care varies substantially.

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### Implications for practice, theory or policy

- Risk assessment is an essential step for the provision of bereavement support according to need.
- The systematic assessment of bereavement risk and provision of support will result in more effective economical use of resources in palliative care.
- These findings may guide individual palliative care services towards evidence-based assessment and intervention and inform palliative care practice standards.

## Introduction

Standards and policies recommend support be provided to family caregivers of palliative care patients, and this support should extend beyond the patient's death.<sup>1–5</sup> Better bereavement outcomes is a goal of palliative care.<sup>6</sup> However, bereavement support offered by palliative care services throughout developed countries is affected by a range of complex issues, including uncertainty about whether the supports provided by these services adequately meet the needs of bereaved family caregivers.<sup>7–10</sup>

Of particular concern is that bereavement support in palliative care tends to be offered to all bereaved persons, irrespective of need.<sup>8,10,11</sup> However, research indicates that within the bereaved population, those experiencing greater distress do not seek help.<sup>10,12–14</sup> This provision of blanket bereavement support means that some bereaved caregivers, possibly those in greatest need, may be overlooked, while others receive support they do not need.<sup>14,15</sup> As greater burdens are placed on the healthcare system, this approach is inappropriate and unsustainable.<sup>8,10,16</sup> Providing bereavement support through effective assessment of need is required, and the public health model of bereavement support articulates a way to achieve this aim.<sup>10,17</sup>

### The public health model of bereavement support

Public health approaches align interventions with need across three groups – the bereaved population (universal intervention), 'at risk' groups (selective) and those with signs or symptoms of a disorder (indicated).<sup>10</sup> Recent pilot testing in a community sample has provided preliminary empirical and theoretical support for the public health model (Figure 1) in aligning bereavement support needs and intervention.<sup>11</sup> By providing services appropriate to the needs of these three groups, palliative care services might better meet the support needs of the bereaved and use resources more efficiently.<sup>10</sup>

Bereavement risk assessment is an essential initial step for the provision of bereavement support according to need. Various points along the care and bereavement trajectory are highlighted as being optimal for assessment.<sup>1,2</sup> The first assessment should ideally be commenced between intake

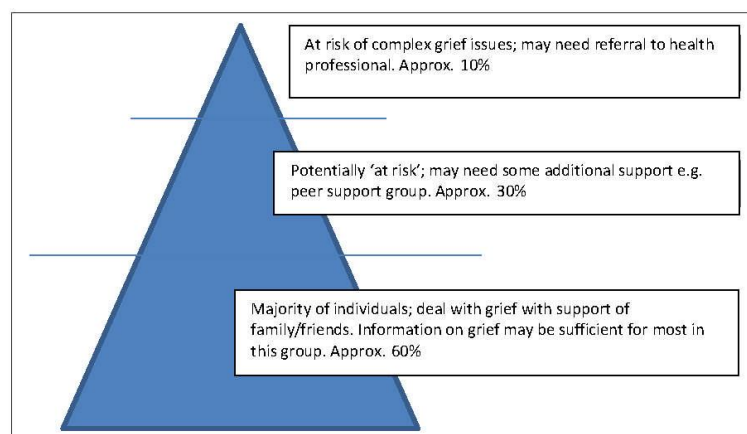
to the service and the patient's death, in order to respond to mental health issues or bereavement support needs in a timely manner. A second assessment should be conducted within 3–6 weeks after the death to ascertain any trauma related to the death. In addition, a phone call to the family caregiver at 12 weeks post-death is recommended to determine whether additional assessment or support is needed. For those identified as being at increased risk of prolonged or complicated grief in the initial assessments, a third assessment should be conducted approximately 6 months following the death.<sup>1,2</sup>

Extensive research has been conducted on complicated or prolonged grief, whereby bereavement distress triggers an intense grief reaction that can endure for an extended period, and may initiate ongoing physical or mental health disorders. Such intense grief tends to interfere with integration and adjustment to the loss, resulting in aversive symptoms, such as yearning for the deceased person, intrusive images and thoughts, rumination, inability to accept the death, a sense of meaninglessness and feelings or behaviours which impede the bereaved person's social or occupational function.<sup>18,19</sup> This research has resulted in the inclusion of Persistent Complex Bereavement Disorder in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5) as a condition for further study and the removal of bereavement as an exclusion factor for the diagnosis of Major Depressive Disorder.<sup>20</sup> Additionally, Prolonged Grief Disorder (PGD) is proposed for inclusion in the forthcoming revision of the *International Statistical Classification of Diseases and Related Health Problems* (11th Revision; ICD-11).<sup>21</sup>

The objectives of the scoping literature review are as follows:

1. To identify bereavement risk assessment measures that may be used to assess grief at different points in the caring and bereavement trajectories (pre-bereavement, following the death of the patient, and for complicated or prolonged grief);
2. To evaluate measures on their psychometric properties;
3. To assess the feasibility of the measures for use in palliative care.





**Figure 1.** The public health model.<sup>17</sup>

## Methods

### Selection of included studies

A scoping review of the literature, using the methodological framework set out by Arksey and O'Malley,<sup>22</sup> was systematically undertaken to capture articles or abstracts in English language citing bereavement measures between 1980 and August 2014. Databases searched were PsycINFO, CINAHL, PubMed and Cochrane Reviews. Key search terms were grief, bereavement, mourning, family caregivers and caregivers, combined with measurement tool, measurement scale, instrument, rating scale, risk assessment, self-report questionnaire and inventory.

Articles citing measures used for similar but unrelated purposes were excluded. Such examples include end-of-life, dying, quality of life, satisfaction with care, survivorship, religion or spirituality or other forms of loss unrelated to bereavement, such as divorce, employment or migration. Articles relating to grief measures used with infants, children and adolescents were also excluded.

Grey literature was also searched using the same search strategies. These included Internet searches of Google, World Health Organization, CareSearch (an online resource of evidence-based palliative care information), the Grey Literature Report and OAIster. Bereavement and palliative care organisation websites were scrutinised for information on grief measures, as well as reference lists in obtained articles and grief and bereavement handbooks.

### Data extraction

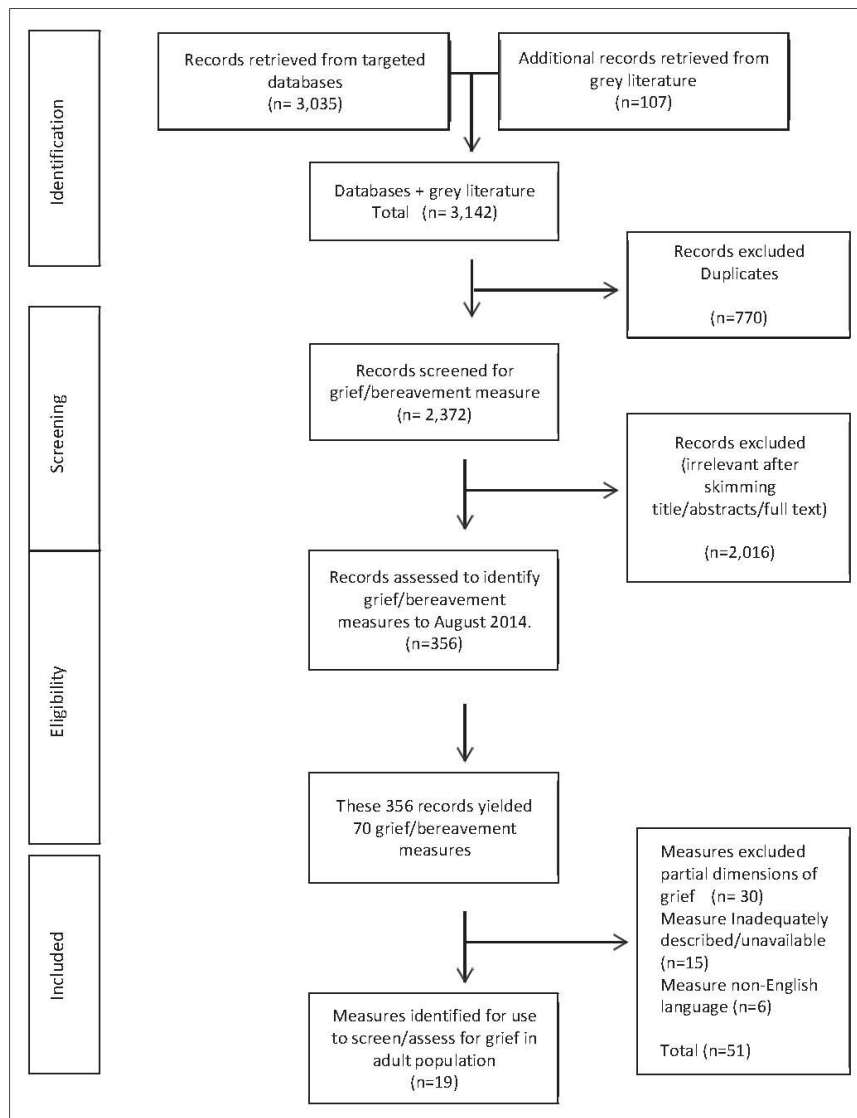
EndNote software version 17 was used to create files for search results. Each database was allocated groups with search terms. Once files were downloaded from each database into EndNote, the articles were then assigned to

sub-groups of duplicates of articles, relevant articles containing grief measures and articles not-relevant. The relevant articles of interest were recorded on Microsoft Excel spread-sheets, listing authors, year and name of publication, country and type of research.

The abstracts of articles of interest were perused for mention of a grief measure. If an abstract did not name measure/s, the full text article was read. Measures were defined as a set of items, grouped in an instrument or tool, which evaluate how a person might feel about himself or herself in relation to his or her grief. Research articles identifying instruments used in the measurement of grief were then critically appraised in relation to reporting of psychometric properties and clinical relevance of the information they might deliver, as well as for feasibility for use in palliative care. The measures were discussed by the research team and consensus reached on their inclusion in, or exclusion from, the search.

## Results

Of the 3142 records screened, 356 records yielded 70 grief measures. Of these, 19 grief measures, published between 1982 and early August 2014, were identified for inclusion in this review. In all, 51 measures were excluded due to a failure to address sufficient dimensions of grief relating to bereavement ( $n = 30$ ); if infrequently mentioned, unavailable, poorly described, may have been precursors to later, commonly used measures ( $n = 15$ ); or not available in English ( $n = 6$ ). A review flowchart is presented in Figure 2.<sup>23</sup> A summary of the properties of eligible measures is presented as appropriate for use with caregivers prior to the death of the patient (Table 1), in the period following the death (Table 2) and for assessing complicated or prolonged grief (Table 3).



**Figure 2.** Flow diagram outlining selection of measures from relevant articles.

### *Pre-death measures of bereavement risk*

Five measures were identified specifically designed to assess grief prior to a death (Table 1). These were three caregiver self-report measures and two staff-administered observational checklists. One checklist was the Bereavement Risk Assessment Tool (BRAT), developed by Canadian palliative care health professionals, based on 10 case studies rated by 36 bereavement professionals, which demonstrated moderate inter-rater reliability. The items include both risk and protective factors stemming from the literature and clinical experience. It

centres on staff observation, rather than direct enquiry of the caregiver's perceptions of his or her emotional state or coping. It also requires staff to be trained in its use and has a large number of complex factors that staff rate subjectively.<sup>24</sup>

The other checklist was the 8-item Bereavement Risk Index (BRI), which exhibited adequate internal consistency when tested for reliability in a community palliative care service. This assessment, which maps to a support protocol, is brief and user-friendly; however, it is based on staff observations, rather than directly asking the caregiver.

**Table 1.** Pre-death measures of bereavement risk ( $n = 5$ ).

Measure	Initial test population, and purpose of measure	Format and items	Psychometric data
Bereavement Risk Assessment Tool (BRAT) <sup>24</sup>	Palliative care family caregivers ( $n$ not reported). To identify those at risk of complex grief prior to patient's death.	40-item, staff observational checklist. Items based on 36 risk factors and 4 protective factors associated with bereavement	Inter-rater reliability for agreement on measure items: Fleiss' kappa ranging between 0.05 and 0.97.
Bereavement Risk Index (BRI) <sup>25,26</sup>	Palliative care family caregivers ( $n = 150$ ) <sup>25</sup> Longitudinal study of bereaved spouses ( $n = 46$ ) <sup>26</sup>	8-item, staff observational checklist completed by nurse at the time of patient's death <sup>25</sup> Completed by researcher in a battery of three measures, before death, and twice following death <sup>26</sup>	Internal consistency: Cronbach's alpha 0.64 <sup>25</sup> BRI psychometric data not reported <sup>26</sup>
Marwit–Meuser Caregiver Grief Inventory (MM-CGI) <sup>27–29</sup>	Caregivers of people with dementia ( $n = 166$ ). To assess grief in caregivers (long term and acute) prior to death of a patient <sup>27</sup> Caregivers of people with acquired brain injury ( $n = 28$ ) <sup>28</sup> Caregivers of people with cancer ( $n = 75$ ) <sup>29</sup>	50-item self-report, 5-point Likert scale, consisting of three subscales	Internal consistency: Cronbach's alpha 0.96 for total grief score, and ranging between 0.90 and 0.95 for subscales <sup>27</sup> Cronbach's alpha between 0.86 and 0.90 <sup>28</sup> Cronbach's alpha between 0.90 and 0.96 <sup>29</sup>
Marwit–Meuser Caregiver Grief Inventory–Short Form (MM-CGI-SF) <sup>30</sup>	Caregivers of people with dementia ( $n = 292$ ). To develop a shortened version, for research, and for cases where attention span is reduced <sup>30</sup>	18-item self-report, 5-point Likert scale, consisting of three subscales	Internal consistency: Cronbach's alpha ranging between 0.80 and 0.83 for subscales <sup>30</sup>
Prolonged Grief–12 (PG-12) <sup>31,32</sup>	Adult caregivers of people with dementia in residential aged care ( $n = 315$ ). To describe pre-death grief and differentiate between grief and depression <sup>31</sup> Adult caregivers of hospice patients ( $n = 60$ ). To measure incidence of PGD <sup>32</sup>	12-item self-report, 5-point Likert scale	Internal consistency: Cronbach's alpha 0.81 for 10 of the 12 items <sup>31</sup>

PGD: Prolonged Grief Disorder.

A modified 4-item version had improved internal consistency and retained predictive validity when compared to the longer version.<sup>25</sup> A modified version of the BRI was also used in a small longitudinal study of spousal bereavement, but the authors reported it to be unsuitable for prospective use without adaptation.<sup>26</sup>

Two self-report measures were originally developed for use with dementia caregivers: the 50-item Marwit–Meuser Caregiver Grief Inventory (MM-CGI), which also has a short form. Initial validation of the MM-CGI showed three factors – personal sacrifice burden, heartfelt sadness and longing and worry and felt isolation – each demonstrated high internal consistency reliability. The scores of the measures are highly correlated with scores on the Beck Depression Inventory (BDI), the Anticipatory Grief Scale (AGS), the Caregiver Strain Index (CSI), the Perceived Social Support–Family Questionnaire (PSSQ-FA) and the

Caregiver Well-Being Scale–Basic Needs (CWBS-BN) subscales,<sup>27</sup> indicating good construct validity. This instrument has good internal consistency when used in caregivers of people with acquired brain injury, where it was found to be highly correlated with the same measures as in the original validation study cited above.<sup>28</sup> While the measure requires modification for use outside dementia, one study conducted with cancer caregivers demonstrated high internal consistency.<sup>29</sup> A short form (18-item Marwit–Meuser Caregiver Grief Inventory–Short Form (MM-CGI-SF)) was also extracted from the longer version and had similar psychometric properties and high correlations with the measures in the original study.<sup>30</sup>

The remaining self-report measure is the 12-item Prolonged Grief (PG-12) Caregiver version, developed from the PG-13,<sup>31</sup> specifically to screen for pre-death susceptibility for PGD.<sup>19</sup> It is brief and targets those at risk of



**Table 2.** Measures of bereavement risk following a patient's death ( $n = 10$ ).

Measure	Initial test population and purpose of measure	Format and items	Psychometric data
Bereavement Experience Questionnaire–24 (BEQ-24) <sup>33</sup>	Bereaved adults within 2 years of bereavement ( $n = 437$ ) with additional validation study ( $n = 297$ ) <sup>33</sup>	24-item self-report, 4-point Likert frequency scale	Internal consistency: Cronbach's alpha ranging between 0.70 and 0.84 <sup>33</sup>
Core Bereavement Items (CBI) <sup>34</sup>	Bereaved adults ( $n = 158$ ) <sup>34</sup>	17-item self-report, 4-point Likert frequency scale	Internal consistency: Cronbach's alpha total grief of 0.91 <sup>34</sup>
Grief Evaluation Measure (GEM) <sup>35</sup>	Bereaved adults: validation sample ( $n = 92$ ); reliability sample, 1 year later ( $n = 23$ ) To assess nature and severity of grief following loss <sup>35</sup>	91-item self-report, 6-point Likert scale consisting of seven sections in total; six scaled sections, with one open narrative section	Internal consistency in validation sample for <i>Experiences</i> section Cronbach's alpha 0.91; <i>Problems</i> section Cronbach's alpha 0.97 Test–retest correlation in reliability sample for <i>Experiences</i> section ( $r = .97$ ); <i>Problems</i> section ( $r = .88$ ) <sup>35</sup>
Grief Experience Questionnaire (GEQ) <sup>36</sup>	Conjugally bereaved adults to suicide, natural causes or accidental death at 2–4 years post-loss ( $n = 57$ ). To differentiate grief related to suicide death from grief related to natural and/or accidental deaths <sup>36</sup>	55-item self-report, 5-point Likert scale consisting of 11 subscales	Internal consistency: Cronbach's alpha ranges for subscales between 0.68 and 0.89, with a total alpha of 0.97 <sup>36</sup>
Hogan Grief Reaction Checklist (HGRC) <sup>37</sup>	Parentally bereaved people recruited from support groups ( $n = 586$ ) for an initial 100-item checklist; $n = 209$ in revised 61-item checklist. To gauge the multidimensional features of grief and bereavement over time <sup>37</sup>	61-item self-report, 5-point Likert scale consisting of six factors	Internal consistency: Cronbach's alpha ranges for subscales between 0.79 and 0.90, with a total alpha of 0.90 Test–retest reliability correlations range between 0.56 and 0.85 <sup>37</sup>
Inventory of Traumatic Grief (ITG) <sup>38</sup>	Elderly widowed residents, 3.5 months following a loss ( $n = 76$ ). To measure maladaptive symptoms of grief <sup>38,39</sup> Bereaved adults within previous 3 years, who had help with their grief ( $n = 250$ ) <sup>39</sup>	34-item self-report, 5-point Likert scale consisting of two factors <sup>38</sup> Dutch version ITG 29-item self-report, 5-point scale, with one single factor <sup>39</sup>	Internal consistency: Cronbach's alpha 0.95 <sup>38</sup> Internal consistency: Dutch version ITG 29-item self-report, 5-point scale, Test–retest correlation ( $n = 29$ ) ranged between 0.41 and 0.91, with total 0.92 <sup>39</sup>
Revised Grief Experience Inventory (R-GEI) <sup>40</sup>	Hospice caregivers following the death of a loved one ( $n = 418$ ). To quantify grief in the context of various relationships <sup>40</sup>	22-item self-report, 6-point scale consisting of 4 subscales	Internal consistency: Cronbach's alpha 0.93 <sup>40</sup>
Texas Revised Inventory of Grief (TRIG) <sup>41</sup>	Bereaved psychiatric outpatients between 2 months and >2 years post-loss ( $n = 57$ ) <sup>41</sup> TIG Expanded: Bereaved adults ( $n = 211$ ) <sup>42</sup> Initially developed as a measure of unresolved grief (TIG) <sup>43</sup>	21-item self-report, 5-point Likert scale consisting of two stand-alone subscales, past (8 items) and present (13 items)	Limited information available for seminal TRIG research. Internal consistency: Cronbach's alpha 0.86; Split-half reliability $r = .88$ (TIG expanded which forms basis of present TRIG) <sup>44</sup>
Two-Track Bereavement Questionnaire (TTBQ) <sup>45</sup>	Bereaved adults ( $n = 354$ ). To gauge grief reaction across time in relation to bio-psychosocial function and ongoing relationship with the deceased <sup>45</sup>	70-item self-report, 5-point Likert scale, consisting of five factors, divided into two domains	Internal consistency: Cronbach's alpha ranged between 0.75 and 0.94 for the five factors, with a total alpha of 0.94 <sup>45</sup>
Two-Track Bereavement Questionnaire (TTBQ2-CG30) <sup>46</sup>	Adults bereaved by traumatic deaths ( $n = 412$ ). To assess for complicated or prolonged grief <sup>46</sup>	30-item self-report, 5-point Likert scale consisting of four factors, across two domains	Internal consistency: Cronbach's alpha 0.91 <sup>46</sup>

TIG: Texas Inventory of Grief.

**Table 3.** Measures of complicated or prolonged bereavement following a patient's death ( $n = 4$ ).

Measure	Initial test population, and purpose of measure	Format and items	Psychometric data
Brief Grief Questionnaire (BGQ) <sup>47-49</sup>	Recipients of crisis counselling following 911 terrorist attacks ( $n = 149$ ). To provide a rapid screening measure of complicated grief >6 months following the death <sup>47</sup> Bereaved community dwelling adults bereaved between 6 months and 10 years ( $n = 915$ ) <sup>48</sup>	5-item self-report, 3-point frequency scale.	Internal consistency: Cronbach's alpha 0.82 <sup>47</sup> Internal consistency: Cronbach's alpha 0.75 <sup>48</sup>
Inventory of Complicated Grief (ICG) <sup>50</sup>	Conjurally bereaved elders ( $n = 97$ ). To assess complicated grief symptoms as distinct from 'normal' grief <sup>50</sup>	19-item self-report, 5-point frequency scale, showing one single factor from original 22-item measure.	Internal consistency: Cronbach's alpha 0.94. Test-retest reliability: 0.80 ( $n = 28$ ).
Inventory of Complicated Grief-Revised (ICG-R) <sup>19</sup>	Data from Yale Bereavement Study ( $n = 291$ ). To validate criteria for diagnosis of prolonged or complicated grief (CG) <sup>19</sup> Conjurally bereaved elders ( $n = 481$ ). To assess complicated grief factors, and the relationship between CG and PTSD <sup>51</sup> Bereaved people in general practice and palliative care ( $n = 276$ ). To identify people at risk of CG <sup>52</sup>	15-item self-report, 5-point frequency scale Shows two factors – separation anxiety and traumatic distress <sup>51</sup>	Internal consistency: Cronbach's alpha total 0.94 Ranging between 0.60 and 0.66 for separation anxiety, and 0.38–0.68 for traumatic distress <sup>51</sup> Internal consistency: Cronbach's alpha total 0.90 <sup>52</sup>
Prolonged Grief–13 (PG-13) <sup>14,53</sup>	Adults ( $n = 424$ ) To compare grief across bereavement, divorce and job loss <sup>53</sup> Bereaved caregivers with PGD ( $n = 86$ ) To examine use of mental health services in people with PGD <sup>14</sup>	13-item self-report, 5-point Likert scale	Internal consistency: Cronbach's alpha total 0.94 <sup>53</sup> Internal consistency: Cronbach's alpha total 0.82 <sup>14</sup>

PGD: Prolonged Grief Disorder; PTSD: post-traumatic stress disorder.

prolonged grief prior to the patient's death. In a study on caregiver burden in hospice caregivers, almost half were found to be at risk of PGD.<sup>32</sup>

### Measures of bereavement risk following a patient's death

Ten self-report measures, developed for a variety of purposes from research to clinical assessment, were identified for possible use to measure caregivers' bereavement support needs following patient death (Table 2).

The 67-item Bereavement Experience Questionnaire (BEQ) was modified to the Bereavement Experience Questionnaire–24 (BEQ-24) to assess three loss domains – existential loss/emotional needs, guilt/blame/anger and preoccupation with thoughts of the deceased – reflective of 'normal' grief.<sup>33</sup>

Similarly, the 17-item Core Bereavement Items (CBI) scale was developed from an earlier Bereavement Phenomenology Questionnaire (BPQ), which had been designed to map grief experience and intensity. The CBI has three subscales: images and thoughts, acute separation and grief. The CBI exhibits high internal consistency and

suitable convergent validity with the Texas Revised Inventory of Grief (TRIG) past and present scales.<sup>34</sup> Researchers have used this measure to associate spiritual beliefs and grief resolution,<sup>54</sup> bereavement outcomes in two ethnic groups<sup>55</sup> and the role of trauma and death anxiety in complicated grief.<sup>56</sup> Being shorter in length and therefore more practical for caregiver use, the CBI measure appears promising for use in palliative care; however, it is considered to be a generalised measure of grief<sup>57</sup> and therefore may not identify those caregivers at risk of poor bereavement outcomes.

The Grief Evaluation Measure (GEM) was developed to provide clinicians with readily accessible information for treatment planning and, in particular, to identify risk of complicated grief. Items were drawn from risk factors identified in the empirical literature. The 91-item instrument covers demographic information, previous health issues and losses, relationships and resources, as well as peri-death circumstances that may impact bereavement distress. At the heart of the instrument are the *Experiences* (58 items) and *Problems* (33 items) sections. A final section invites the caregiver to comment. Internal consistency reliability was high for the central *experiences* and *problems*



sections and correlated well with other measures such as the Inventory of Complicated Grief (ICG) and the Impact of Events Scale-Revised (IES-R).<sup>35</sup> The GEM is psychometrically sound and comprehensive, but its complexity and length make it impractical for use in palliative care. Most palliative care services do not have face-to-face contact with caregivers following the patient's death, which reduces the likelihood that a complex and lengthy measure would be understood, completed and returned to the service.

The Grief Experience Questionnaire (GEQ) was developed to compare grief in those who had lost someone to suicide, with those who had lost someone to natural or accidental causes. It comprises 11 subscales that cover somatic and general grief reactions, meaning making, social support, stigmatisation, guilt, responsibility for the death, shame, rejection, self-destructive behaviour and reactions exclusive to suicide survivors. While many of these are common grief experiences, Barrett and Scott<sup>36</sup> state that some features are more pronounced or unique in those grieving a suicide loss. A subsequent study found that the measure was suitable for both clinical and research use in all grief, not suicide alone, but the authors note that further research is needed before being applied to palliative care.<sup>38</sup>

The Hogan Grief Reaction Checklist (HGRC) was based on data derived from focus groups with bereaved parents. Exploratory Factor analysis of this data yielded six factors – despair, panic behaviour, blame and anger, detachment, disorganisation and personal growth.<sup>37</sup> The 61-item HGRC would also seem to be very long and complex to be of practical use for post-death assessment in palliative care.

The 22-item Revised Grief Experience Inventory (R-GEI) was developed from the earlier 135-item Grief Experience Inventory (GEI), with each item scored as a yes/no response. The four R-GEI subscales explore existential concerns, depression, feelings of tension and guilt and physical distress. The R-GEI may have practical application in the palliative care context, although the authors state that it provides a framework for clinicians to work with routine grief responses<sup>40</sup> which may not be suited to identifying 'at risk' caregivers.

The 34-item Inventory of Traumatic Grief (ITG) was developed to examine symptoms for 'pathological' grief, a term its developers originally used interchangeably with 'traumatic grief'. The researchers saw two main symptom clusters of separation distress and traumatic distress. The ITG is an expanded version of the ICG which will be discussed in the next section.<sup>38,39</sup>

The TRIG was developed from the earlier Texas Inventory of Grief (TIG) as a brief measure of unresolved grief;<sup>43</sup> however, as the items were derived from both normative and atypical grief responses, it is considered to be a measure of 'normal' grief.<sup>44,50,57</sup> The TRIG comprises two

subscales which may be used independently – *Past* behaviour (8 items) and *Present* feelings scale (13 items).<sup>57</sup> The TRIG has been used to measure adjustment and grief intensity in hospice caregivers, from prior to the death until 13 months post-death.<sup>59</sup>

Finally, the Two-Track Bereavement Questionnaire (TTBQ) was developed to assess grief responses across time. Factor analysis showed five factors that could be broadly categorised within two domains – the bereaved person's bio-psychosocial function (Track 1) and ongoing connections with the deceased (Track 2).<sup>45</sup> While this measure is psychometrically sound and gathers comprehensive, clinically useful information, its complexity and length pose a problem for palliative care use. The TTBQ has recently been developed into a shorter 30-item measure, the TTBQ2-CG30, to assess complicated grief in terms of the ongoing relationship with the deceased and the impact on function.<sup>46</sup> As services have limited to no contact with caregivers after the death, this shorter version may have application to palliative care and warrants further research to determine its suitability.

Other measure cited in the literature, and not included in this review, was the BPQ,<sup>60</sup> as it was later incorporated into the CBI.<sup>34</sup> Likewise, the TIG<sup>43</sup> was expanded into the TRIG,<sup>44</sup> and the lengthy 135-item GEI by Sanders and colleagues was modified to form the R-GEI.<sup>40</sup> The BEQ by Demi in 1984 was revised to the BEQ-24 to address a number of theoretical issues in the earlier instrument.<sup>33</sup> The Grief Measurement Scale (GMS), while being mentioned in some literature,<sup>50,61,62</sup> has proved difficult to locate. The GMS included items relating to anxiety, depression and general grief, while omitting the more serious symptoms of complicated grief.<sup>50</sup> The IES and IES-R were used as measures of grief in research studies,<sup>63</sup> but were excluded in this review because they are measures of traumatic stress<sup>64,65</sup> rather than grief.

### *Measures of complicated or prolonged bereavement risk following a patient's death*

Four self-report measures were developed specifically for complicated or prolonged grief, and may be suited to assess poor adjustment to bereavement 6 months post-death and beyond. Three of these measures were developed from research determining how the symptoms of complicated or prolonged grief are distinct from 'normal' grief, as well as depression and anxiety. These well-validated and widely used measures<sup>57</sup> are the ICG,<sup>50</sup> which also has a revised 15-item version (ICG-R),<sup>19</sup> and the PG-13, an algorithm for diagnostic criteria for PGD.<sup>19</sup> The ICG and the ICG-R were used to assess grief across various grieving populations such as spousal<sup>50</sup> and parental loss,<sup>66</sup> those bereaved following traumatic events<sup>67</sup> and suicide<sup>68</sup> and in settings such as mental health,<sup>69</sup> intensive care,<sup>70</sup> palliative care<sup>71</sup> and oncology.<sup>72</sup> The PG-13 has

also been used across a variety of research including refugee populations<sup>73</sup> and Motor Neurone Disease (MND) caregivers.<sup>74</sup>

The Brief Grief Questionnaire (BGQ), also known as the Brief Complicated Grief Questionnaire (BCGQ), was developed as a brief screening instrument for complicated grief following the 9/11 terrorist attacks in the United States.<sup>47</sup> This measure has also been used to determine the prevalence of complicated grief in a large sample in Japan, demonstrating cross-cultural applicability. Its psychometric properties remain adequate across studies.<sup>48,49</sup>

## Discussion

The primary aim of the scoping review was to identify bereavement measures that could be used by palliative care services to screen for risk of poor bereavement outcomes in caregivers at three points in time: before the death of the patient, in the weeks following the patient's death and 6 months following the patient's death.<sup>2</sup> These measures were evaluated based on their psychometric properties and feasibility for use in palliative care settings with the intention of informing a bereavement risk assessment protocol based on the public health model of bereavement support<sup>17</sup> that aligns bereavement risk with service provision.

It is notable that the majority of the bereavement measures had acceptable psychometric properties. However, validity and reliability were not always reported consistently. The measures were initially developed for a variety of purposes, ranging from screening to diagnosis, treatment planning and assessment of efficacy of interventions in both clinical and research contexts. They were used across a wide variety of populations and settings, and although some had been used in palliative care, or for family caregivers of people with life-limiting illnesses, only one had been developed specifically for palliative care.<sup>24</sup> A number of measures were developed for the assessment or screening of complicated or prolonged grief later in the bereavement trajectory.<sup>19,47</sup>

There are a number of issues that need consideration when assessing bereavement risk in palliative care. Palliative care provides a window of opportunity to assess grief and bereavement needs in the lead up to the patient's expected death.<sup>75</sup> Generic measures arguably should not require modification for use in palliative care if they are measuring a given construct in other populations.<sup>15</sup> However, it is clear that situations faced by caregivers in palliative care are also unique, in that there are often additional issues that may affect grief responses, assessment and the provision of support.<sup>6,75,76</sup> As such, balancing the need for theoretically sound and empirically validated measures, with robust psychometric properties, alongside the practical need for a tool that is acceptable and feasible for use in busy clinical settings, remains a challenge.

## Implications for palliative care practice

It is important to consider the model of care and funding source of a service, particularly in light of the rapidly changing environments we are presently witnessing. These include changes to how palliative care services are delivered and to whom, alongside social and cultural changes inherent in any population.<sup>15</sup> Community-based services generally have longer contact with patients and caregivers, while inpatient or consultative services in hospitals may only have contact with patients and caregivers nearer end-of-life. Any bereavement risk assessment model needs to be developed within a range of referral pathways, not only counselling or therapy.<sup>10,77</sup>

A recent trend towards late referral to palliative care and shorter lengths of stay mean staff have little opportunity to build a comprehensive picture of patient needs, as was done previously with the use of staff observations and checklists.<sup>77,78</sup> While family caregivers are considered to be a part of the unit of care in a palliative care service,<sup>5</sup> and staff accept that bereavement support is important, the primary focus nevertheless remains on end-of-life care and the patient's comfort and symptom control.<sup>79</sup> While lengthy measures are likely to extract comprehensive information, they are inappropriate when a family caregiver's time with the patient is limited, or when caregivers are focused on the needs of the dying patient.<sup>80</sup>

The lead up to the death may be stressful to caregivers and caregiver burden may become confounded with grief. Conflation of these constructs clouds the issue of assessment and must be taken into account when assessing grief and bereavement support needs.<sup>80</sup> This raises the question as to what services need to assess in relation to what support they can, or should, provide.

Assessment following the patient's death often poses other challenges. Many services conduct follow-up via mail and/or telephone,<sup>8</sup> which may not allow for caregivers to accurately convey responses about complex emotional states. In turn, this may affect the validity of their responses. Furthermore, while standards recommend that bereaved former caregivers identified as being at increased risk of complicated or prolonged grief should be followed-up again at 6 months post-death,<sup>1,2</sup> this is not yet established practice in palliative care.<sup>8</sup> It is likely that staff would require upskilling so that they can undertake these assessments to identify and support caregivers pre- and post-bereavement appropriately.

With the above constraints in mind, we identified 19 grief measures as having adequate psychometric properties and potential applicability for use in palliative care. Previous reviews have identified grief measures within a broad variety of instruments, from often overlapping domains, for use in palliative care.<sup>75,81</sup> This in itself is problematic, as it not only makes comparisons of measures difficult but may possibly impede consensus on a bereavement



risk assessment protocol.<sup>82</sup> This study has classified measures in line with recommended standards,<sup>1,2</sup> as well as aligning bereavement needs with support in accordance with the public health model.<sup>17</sup> If a more robust assessment of caregiver bereavement support needs can be made between admission and separation from the service, it is expected that the follow-up after the death will be more targeted to those in need of support, rather than following up the majority who integrate their loss over time.

### Limitations and future directions

While hand searches of books, articles and organisations were conducted, and grey literature was searched, it is likely that sources were overlooked due to the immensity of the subject area. However, we are confident that the 19 measures included here were salient, as they were commonly cited in the literature. Psychometric properties and/or the theoretical frameworks of measures have not been reported consistently in the searched articles, so there may be ambiguity for the reader who is looking for clear comparisons between instruments and their utility along the caring and bereavement trajectories.

Future research is needed to investigate why palliative care services have not adopted existing bereavement risk assessment measures as routine practice.<sup>8,75</sup> Undoubtedly, bereavement risk assessment is multifaceted and complex. As such, implementing a bereavement risk assessment model for palliative care is a departure from current practice and will not be without its challenges.

### Conclusion

The aim of this scoping review was to identify bereavement risk assessment measures suitable for use in palliative care, congruent with the public health model of bereavement support. This review has centred on the assessment of grief, rather than a broad range of related palliative care domains, which have been the focus of other reviews.<sup>15,81</sup> We identified 19 frequently cited grief measures that were categorised for use with family caregivers at three points in time – before the patient's death, in the period following the death and at 6 months post-death – to screen for prolonged or complex grief issues. As stated above, the complexities of grief, bereavement and palliative care make it difficult to define the necessary attributes when considering measures for a bereavement risk assessment model. Issues relating to the unique conditions inherent in palliative care, such as, for example, conflation between caregiver burden and grief and service contact with caregivers, must be resolved before moving forward with a bereavement risk assessment model. This review is an important step in the process of moving towards appropriate assessment of bereavement risk and better bereavement outcomes for people caring for a patient or family member in palliative

care. Timely and suitable assessment and targeted support according to need would be a leap forward in the provision of ethical, effective and cost-effective bereavement support in palliative care.

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The authors declare that there is no conflict of interest.

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## CHAPTER FIVE

### **The Reference Group: Exploring Bereavement Risk Assessment Practice in Palliative Care**

“The combined results of several people working together is often much more effective than could be that of an individual scientist working alone.”

- John Bardeen (1908-1991)

#### **Chapter Overview**

Chapter Five gives a detailed account of the reference group proceedings that took place in the second phase of the study. The grief measures identified in the scoping review of the literature (phase one, as outlined in the previous chapter) were presented to a reference group comprising health professionals and a bereaved former caregiver (n=9) from five palliative care services. The same group met on three separate occasions to develop the bereavement risk assessment model that was originally proposed using existing grief measures. The data from the stakeholder group has been published as a research article, titled “Exploring barriers to assessment of bereavement risk in palliative care: perspectives of key stakeholders” in *BMC Palliative Care*, which is an open-access peer-reviewed journal with relevance to hospice, palliative care and chronic illness. It was published online, October 14, 2015. The paper provides a detailed account of the issues affecting bereavement risk assessment. These issues will need to be overcome before bereavement risk assessment will become standard practice. The article concludes with the reference group health professionals suggesting that a new brief grief measure be developed for use in palliative care.





RESEARCH ARTICLE

Open Access



# Exploring barriers to assessment of bereavement risk in palliative care: perspectives of key stakeholders

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## Abstract

**Background:** Palliative care standards advocate support for grieving caregivers, given that some bereaved people fail to integrate their loss, experience ongoing emotional suffering and adverse health outcomes. Research shows that bereavement support tends to be delivered on an ad hoc basis without formal assessment of risk or need. To align support with need, assessment of bereavement risk is necessary. The overall aim is to develop a bereavement risk assessment model, based on a three-tiered public health model, congruent with palliative care bereavement standards for use in palliative care in Western Australia. The specific aim of this phase of the study was to explore the perspectives of key stakeholders and to highlight issues in relation to the practice of bereavement risk assessment in palliative care.

**Methods:** Action research, a cyclical process that involves working collaboratively with stakeholders, was considered as the best method to effect feasible change in practice. The nine participants were multidisciplinary health professionals from five palliative care services, and a bereaved former caregiver. Data were obtained from participants via three 90 min group meetings conducted over five weeks. An inductive thematic analysis approach was used to analyse data following each meeting until saturation was reached, and the research team was satisfied that the themes were congruent with research aims.

**Results:** Existing measures were found unsuitable to assess bereavement risk in palliative care. Assessment following the patient's death presented substantial barriers, directing assessment to the pre-death period. Four themes were identified relating to issues in need of consideration to develop a risk assessment model. These were systems of care, encompassing logistics of contact with caregivers; gatekeeping; conflation between caregiver stress, burden and grief; and a way forward.

**Conclusions:** These group discussions provide a data-driven explanation of the issues affecting bereavement risk assessment in palliative care settings. A number of barriers will need to be overcome before assessment can become routine practice. We recommend the development of a brief, pre-death caregiver self-report measure of bereavement risk that may empower caregivers, lead to early intervention, and allow staff to remain focused on patient care, reducing burden on staff and palliative care services.

**Keywords:** Grief, Bereavement, Bereavement risk assessment, Palliative care, Family caregivers

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## Background

The loss of a loved one is a normal, but nonetheless emotionally painful, life event that the majority of people integrate into their lives [1]. However, a minority of people, approximately 10 % of bereaved individuals, find adjustment difficult [2, 3]. Integration of the loss tends to be very difficult for these people and they may experience ongoing emotional suffering [4] which interrupts social, occupational, and physical functioning [5, 6]. This minority of individuals are more likely to be at risk of poor bereavement related outcomes such as poorer mental and physical health, and diminished quality of life [7, 8]. There is evidence to suggest that this minority of individuals suffer higher rates of cancers and cardio-vascular problems [9] as well as being at greater risk for suicide [10]. These complicated or prolonged grief reactions are supported by empirical research and criteria have recently been proposed for diagnostic nosology [11, 12]. Discussion on descriptive terms for this syndrome of reactions to grief has been contentious [13, 14]. Some argue that the term complicated may convey difficulty, whereas prolonged grief may provide clinicians with greater clarity, although Prigerson, Vanderwerker, and Maciejewski [3] caution against duration as the principle criterion. Despite such debates, few clinicians or researchers would contest that there are a minority of individuals adversely affected by grief and who require support to ameliorate such suffering [15]. In view of such concerns the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) has categorised Persistent Complex Bereavement Disorder as requiring further investigation with a 12 month post-death period required before potentially meeting criteria for treatment [16].

Unlike many health settings, palliative care includes family caregivers within the unit of care [17] and, as such, offers a unique opportunity to assess grief and bereavement [18]. Palliative care standards and policies promote the provision of support to grieving caregivers where necessary [19]. Bereavement standards for specialist palliative care services [20] suggest assessing caregivers throughout pre-death contact with the service, using a structured assessment process and screening tool. As soon as possible following the death, caregiver distress due to the patient's condition in the lead-up to death should be assessed, and within 12 weeks post-death all caregivers should receive follow-up telephone calls. The standards also recommend that at approximately six months after the death, those previously identified as 'at risk' should undergo further assessment with a validated measure such as the PG-13 (Prolonged Grief -13) [15]. However, research shows that bereavement support tends to be delivered on a piecemeal, ad hoc basis without formal assessment of risk or need [21–23]. This often results in support being offered to those who may not need it while others who would benefit are overlooked [24, 25]. This practice of

blanket bereavement support contradicts findings showing grief intervention may be ineffective, or even harmful, for the majority who manage to integrate the loss into their lives [2, 26].

A three-tiered public health model of bereavement support articulated by Aoun, Breen, O'Connor, Rumbold, and Nordstrom [27] aligns intervention with need and is congruent with bereavement standards and policies. This model incorporates a low risk group of bereaved people that are likely to adjust in time with the support of family and friends; a medium risk group that would benefit from a volunteer-led, or peer support group, to prevent the development of ongoing issues; and a high risk group that would most likely require formal support from health professionals. Empirical support for this model has recently been demonstrated in a population-based survey [2].

To provide appropriate support in accordance with this model, bereavement risk assessment is the logical first step. Bereavement risk assessment in end-of-life care has been identified as a key indicator of quality practice [28]; however, at present, the majority of palliative care services do not use systematic, evidence-based methods to assess caregiver distress including bereavement risk [29]. Assessment is often centred on multidisciplinary team opinion and staff observation using in-house checklists [18, 30, 31]. An effective and reliable model of assessment is necessary to move towards best practice. The need for such a model has been supported internationally by palliative care services in 12 countries [32], as well as by local palliative care service providers, who identified bereavement risk assessment as a high priority [30] which provided the catalyst for this project.

The overall aim was to develop a bereavement risk assessment model for palliative care that would be congruent with standards and policies [20] and that would also be feasible for use in palliative care in Western Australia. As a first step in achieving this aim, we worked in consultation with a reference group comprising members from key Western Australian palliative care stakeholders via a series of group interviews. Where appropriate, the model would incorporate the use of existing grief measures, which were identified in a scoping review of the literature [33]. These measures were presented to the reference group for consideration as to their applicability for palliative care as part of the intended model. The specific aim of this phase of the overall study reported here was to explore the perspectives of key stakeholders in the reference group and to highlight issues in relation to the practice of bereavement risk assessment in palliative care.

## Methods

Data from the stakeholder discussions reported in this paper constitute part of one cycle within an overarching action research study. A key strength of action research



is its capacity to tap local knowledge in research problems that relate to context-specific practices [34]. Action research is aimed towards intervention to bring about improvement in practice in a cyclic process of reflection, action and evaluation by the participants in the research activity [35–37]. While there are various definitions of action research the phase reported in this paper accords with Hart and Bond's [35] professionalising type of action research where the research problem emerges from professional practice, is defined by the professional group, and resolution of the problem leads to enhanced professionalization of the service.

A characteristic and strength of action research is that the stakeholder participants have an active role in decision-making, while the investigator, rather than holding expert knowledge, takes the role of facilitating communication between group members [38]. The first author worked in palliative care clinical practice in the past, and as such, holds an insider perspective [39], which can be helpful on issues relating to clinical practice. However, there is also distance given the stakeholder group members were not known professionally to the first author. A reflexive journal was maintained in order to question assumptions and values and to generate critical enquiry.

Data were obtained from ongoing discussions with, and interaction between, the key stakeholders which enabled a range of perspectives, a shared understanding [40], and obstacles and potential solutions to emerge in the dialogue [41].

#### Participants

Health professionals were recruited from five palliative care sites. The services were from government and non-government sectors. They included an in-patient palliative care unit, a consultative service in a major teaching hospital, a psycho-oncology service and two community-based domiciliary services. The reference group comprised nine members: two clinical nurses; a palliative care physician; a social worker; a psychologist; a counsellor; a psychosocial services manager; a chaplain; and a bereaved former caregiver who also worked as a palliative care volunteer. Ages ranged between 25 and 67 years (Mean 49.8), and years of experience ranged from less than a year to 25 years (Median 9 years). Most participants knew each other professionally.

#### Procedures

The first author met with the managers of palliative care services in Perth, Western Australia in 2013 to capture operational information about the services. Requests for expressions of interest were sent to management at eight palliative care services, outlining what was required for participation in the project. Stratified sampling was used

to select interested participants to represent the range of job designations across the various services and resulted in a group of health professionals typical of a palliative care multidisciplinary team, representing the breadth of models of care and services.

Once the reference group of key stakeholders was formed, three meetings were held in a centrally-located metropolitan health service meeting room. The second meeting was two weeks after the first, and the third meeting followed three weeks after the second meeting. The first author facilitated the meetings and digitally recorded the discussions, which were transcribed following each meeting. All meetings lasted 90 min.

The first meeting began with a discussion of the terms of reference for the group meetings, a brief background to the research question and the research objectives. The group was then asked for feedback on what they believed were necessary attributes of a bereavement risk assessment model for palliative care.

In the second meeting, existing self-report grief measures identified in a scoping review of the literature [33], were presented to the group and discussed. Seven measures from the scoping review were excluded: two were staff observational check-lists; one was a precursor to a later measure; one was a shortened version of a longer measure unavailable at that time; another related to suicide bereavement; one had yes/no responses to normal grief items; and one was a lengthy measure of normal grief. The 12 remaining measures were potentially suitable for use in palliative care at one of three time points; for use before the patient's death ( $n = 3$ ); in the month following the patient's death ( $n = 5$ ); and for assessing complicated grief at 6 months or beyond ( $n = 4$ ). These times were in accordance with bereavement standards recommendations [20, 28]. Copies of the measures, and a summary of research articles pertaining to the measures, were given to participants who agreed to return to their services and discuss the materials with their multidisciplinary teams.

The third meeting was used to explore in detail each of the measures presented at the previous meeting, and to examine their suitability for a bereavement risk assessment model.

#### Ethics approvals

In compliance with the Helsinki Declaration, Human Research Ethics Committee (HREC) approvals were obtained prior to commencement from two major teaching hospitals and the university: Royal Perth Hospital (approval number EC2012/167), South Metropolitan Health Service (approval number R/13/17) and Curtin University (approval number HR30/2013). All participants gave written consent to participate in the research.

### Analysis of data

Data were analysed using an inductive thematic analysis approach in accordance with Braun and Clarke's [42] six phases. Each digital audio recording was repeatedly listened to by the first author to maximise familiarity with the semantic content. The recordings were transcribed verbatim by the first author as soon as possible following each of the meetings. Each transcript was manually coded and preliminary themes were developed prior to the next meeting, allowing the first author to commence each meeting with a summary of interim findings which was confirmed by participants. The feedback from the participants during these meetings, and in telephone and email correspondence between them and the first author, were also used as data. Further scrutiny of transcripts and interim analyses by the research team revealed that saturation had been reached with sufficient information from the participants to illustrate the issues across the different services [43]. The themes have been illustrated below using the participant's own words, thus retaining participants' viewpoints.

### Results

Thematic analysis of the data revealed four themes in relation to potential use of existing measures. These were systems of care, encompassing logistics in contacting caregivers; gatekeeping; conflation between caregiver stress, burden and grief; and a way forward. The first three themes are considered in the context of pre and post-death assessment concluding with a way forward.

#### Pre-death assessment of grief

The pre-death period was regarded as providing the best opportunity for assessment because this is when most services have face to face contact with caregivers. Three pre-death measures were considered by the reference group in detail. The Marwit-Meuser Caregiver Grief Inventory (MM-CGI) [44] received the greatest support, with the short form version [45] deemed unable to capture sufficient information. However, because the MM-CGI was developed for family caregivers of people with dementia, the items would require considerable re-working and subsequent validation before being of potential use in palliative care. The Clinical Psychologist noted that re-wording items on the measure "... might affect the factor structure of the questionnaire." She gave an example of an item on the MM-CGI relating to the closeness of a loved one, stating: "...cognitive decline and connectedness with my family" may be a different experience "through the experience of cancer and caring for someone [when] it actually increases the connectedness."

In considering Prigerson and colleagues' PG-12 caregiver measure [46], participants found an item relating to "moving on" unhelpful, and believed this measure could

confuse caregivers. The Bereaved Former Caregiver said she "*would be put off if I was asked to rate that.*" The Clinical Nurse Manager from the community service said that their service would not use it, stating: "*it's too early to expect someone to have moved on. To be honest, if I was a carer, I think I'd be offended by that.*"

While the pre-death period seemed optimal for the assessment of caregiver bereavement needs, discussion centred on the many issues affecting bereavement assessment in palliative care. Themes emerged in relation to challenges stemming from systems issues, such as differences in service models which affect patient contact and the logistics of assessment when a patient is near death. Strongly woven into these issues was a tendency toward staff gatekeeping in order to shield family caregivers from emotionally loaded situations thus adding to their burden. Conflation between grief and caregiver stress and burden also emerged as a salient theme.

#### Systems of care

Systems issues related to each service's model of care and funding source which influenced staffing, length of patient stay in a service, and type of support they could provide. By necessity patients often move between the different types of services where they are "...going to probably be connected with a range of different services, because of the interdisciplinary approach that a specialist palliative care service" uses (Support Services Manager, community service). The Physician from the in-patient unit stated: "...people move around the system, contacting community services, hospice services and we try to be aware of that."

Because patients use multiple services there is often no clear delineation as to which service is responsible for bereavement care. The Physician added that when people may "...need access to bereavement services... there's a case for where the responsibility should lie, or if there's duplication of services...there can be a predominant service they [patient and family] have been involved with. That's the most appropriate thing for them, but I think it's awfully ad hoc". Compounding this, without medical records available across services, information as to whether support has been accessed by family caregivers is rarely available.

As patients move around the system and between multiple services, there is a potential for them, and caregivers, to be missed between services. As the Bereaved Former Caregiver said: "*I do believe that 'slipping through the system' [being missed between services] unfortunately happens a lot. I wasn't in a system where anybody phoned me. I as the carer needed help. I didn't know where to go.*"

Where patients are in the care trajectory influences what model of care they receive. For example, a community domiciliary service generally has referrals earlier in the palliative care trajectory, whereas a consultative service



in a major hospital may only receive referrals when all other treatment options have been exhausted and the patient is near end-of-life. Contact with patients, and consequently their caregivers, would strongly influence the logistics of when, or if, a measure would be administered:

*"When I think about the sort of situations we have and the acuity and intensity, rapid changes, and multiple people involved with family and complicated circumstances, some people are absolutely in no shape to engage in any of this sort of discussion actually."* (Physician, in-patient unit)

Further challenge to assessment relates to the provision of appropriate support services, either within the palliative care service itself, or as part of a referral pathway to external services. Some reference group members questioned the use of measures if the relevant support was unavailable:

*"[An assessment tool] needs to be seen within a service context, because to just apply it without any context whatsoever, you are then up against this issue of, well, how valid is it going to be?"* (Psychosocial Support Services Manager, community service)

#### Gatekeeping

Gatekeeping, as a process of deciding on the allocation of services [47], was evident in the participants' reticence to engage caregivers directly in relation to their emotional needs. As noted by the Clinical Nurse Manager from the community service:

*"We've all discussed that we wouldn't do the assessment as we do the admission process, so it was waiting 'til people go into that deteriorating phase, but not into the terminal phase, because we want to sort of gauge that... you're a little hesitant to actually pick that time... It would just be overwhelming."*

Concern was expressed about being sensitive towards caregivers particularly in relation to asking personal questions. As the Physician said in relation to the use of a clinical assessment tool, it *"...is a very sectioned process, and working out private information for people."*

However, the Bereaved Former Caregiver, when questioned as to whether she would have felt overwhelmed by 'insensitive' questions, indicated that caregivers have a choice as to whether or not they engage, stating that *"I personally wouldn't have taken offence...I guess if you're not willing to do it, you just ignore it. And I think it comes with when you're ready."*

The Psychologist suggested that asking another family member, or friend, to assess how they believed the caregiver was coping would be beneficial; however, others believed

this would be unworkable. The Physician responded, stating: *"I need to think a bit about that component of the assessment which may require a carer to conform...which is again why I say our team assessment is very much a case of getting a sense of the whole situation. Sometimes the primary carer seems to change over the course of time they are with us."*

Alongside the desire to protect caregivers from further distress there was a preference for an informal chat rather than engaging the caregiver in a direct and formal discussion about how they're coping. As the Clinical Nurse Manager from the community service pointed out: *"...it's going to be more of a conversation that you have as you go to the car as to whether they would be part and parcel of this [self-report assessment]."*

The participants believed that it was preferable to gauge the family caregiver's journey through observation and by looking at where they were in the palliative care trajectory, rather than using a formal measure by *"...having a look at how the person moves through the process. It's not always going to be possible to apply a tool. It's going to be based upon observation [and] interaction"* as noted by the Psychosocial Support Services Manager from a community service. He added that by the time a patient reaches end-of-life, the multidisciplinary team has *"...been able to come to a view... on the basis of a picture that's emerged over a period of time, that can help influence whether you know that person is identified as being at low, moderate, or high risk."*

Observation, informal chat, intuition, and guesswork were prioritised over formal assessment of the caregiver:

*"I guess part of our job in hospice care is to walk along with them [patients and families] and some of those things are appropriate, and some of them do pass because the experience changes them. And that's why those interactions and discussions that come from that place are very important, because you know people can say 'I had this conversation last night and I sense it was an issue'."* (Physician, in-patient unit)

The participants valued the professional judgement that is at the core of their multidisciplinary team's assessment. However, there were flaws in checklists and as noted by the Physician: *"...the information is usually left and filled-out at the time of the death, when it should have been filled-out sooner."*

In spite of problems relating to the accuracy of information on the checklists filled-in by staff regarding their observations of caregivers, they were still thought valuable in building an overall picture:

*"Our team assessment is very much a case of getting a sense of the whole situation, who the different people*

*are...the tick boxes were just to give the team a reminder to attend to things that they can head off along the way...for us it's more about a team sense of what the issues will be. It is just purely reminding us of issues as we come across, that as a team we sort of say 'what do we think? How can we follow up?'"* (Physician, in-patient unit)

#### *Conflation between caregiver stress, burden and grief*

Caregiving is a time of potential high distress given the likelihood of caregiver burden during the patient's illness [48] where distress might cloud assessment. The Counsellor from a community service pointed out:

*"...there are significant milestones for people in grief... three months and sometimes 12 months can be a significant time when you can catch a person in a bad week".* The Social Worker from the consultancy service agreed stating: *"when I do a follow-up in a year, you actually get more people coming back saying 'I'm not doing okay.' It could be because it is around that year anniversary."*

Further complexity may be added to assessment by other factors:

*"The person who is generally caring for the person who is dying, is probably caring for a lot of other people... it's generally the mother, but not always. One of the aspects I come across quite a lot is that when it comes to assessing how people are grieving as a family, there's never two people on exactly the same page, and then that becomes complex. So I guess, the person about who's being assessed, is about who they are supporting as well."* (Counsellor, community service)

A further complicating issue was the need to assess trauma as well as grief at times. This would not be required as routine assessment but would be helpful in screening for the likelihood of posttraumatic stress disorder (PTSD) so that timely referral and intervention might avoid later complex issues:

*"At our meeting today we were discussing someone who had died during the week who had one of those catastrophic bleeds. The son was the one who discovered it. There's trauma as well as grief in the event of the death."* (Counsellor, community service)

This conflating of grief with other psychological issues reflects a lack of clarity about the purpose of assessment, and a tendency to focus on immediate needs related to caregiver stress in order to provide a solution:

*"We're also talking about what services need to do in order to discharge their obligations to people. Who do they contact to make sure they identify people who may need extra help?"* (Physician, in-patient unit)

*"I guess for me it's a question too of what are we assessing for? Are we assessing to identify people who are at risk of PGD [Prolonged Grief Disorder]? Or are we assessing what are the issues that are confronting particular people that will allow a service to say, 'these are the things that this person might need to deal with what has just occurred in their life?'"* (Counsellor, community service)

#### *Post-death assessment of grief*

Asking participants to choose measures for use in the post-death period proved more challenging than at pre-death, largely because services have little or no face-to-face contact with family caregivers. For the immediate post-death period, five measures were considered; the Core Bereavement Items (CBI) [49]; the Grief Evaluation Measure (GEM) [50]; the Hogan Grief Reaction Checklist (HGRC) [51]; the Two-Track Bereavement Questionnaire (TTBQ) [52]; and the Texas Revised Inventory of Grief (TRIG) [53]. Of these, the GEM's 'experiences' section, and the TTBQ were both considered as yielding the most comprehensive and clinically useful information; however, both were deemed overly long and complex for telephone administration. The shorter CBI and TRIG measures were considered as alternatives, but concerns were raised in relation to their potential to screen for prolonged or complex grief issues after the death. The HGRC likewise was regarded as picking up on 'normal' grief, but was thought to have an added disadvantage of 61 items, which would be particularly unwieldy via telephone.

Measures proposed for PGD at six months following a patient's death were the Inventory of Complicated Grief (ICG) and its revised version (ICG-R) [54]; the Prolonged Grief - 13 (PG-13) [12]; and the Brief Grief Questionnaire (BGQ) [55]. The services do not assess bereaved former caregivers for PGD or Complicated Grief (CG) at six months, and as such, the reference group health professionals had difficulty considering the prospect of doing so due to present systems issues, especially funding constraints. As the Clinical Nurse Manager said: *"I didn't have any huge feelings about any of them [measures for CG or PGD] to be honest with you."* The community service she represented kept caregivers *"...on the books for 4 to 6 months, and if one of the staff feels that they need to stay longer than that, then so be it."* The Clinical Nurse Manager from the consultancy service stated: *"We just don't have contact with carers at this time. We don't have the resources to call. This [a measure for prolonged or complicated grief at six months] isn't something we would use."*



### Systems of care

There was agreement that an issue for services was the length of time bereavement support could be offered to people for whom they did not receive funding:

*"Certainly it is for us, and I think it's an issue for a lot of specialist palliative care services, the very nature of how we're structured, the bereavement support we can provide is very limited, and often bereavement support is very closely identified with specialist palliative care, when very clearly, they're actually separate. They're related in relation to a service, but they're [bereavement support and palliative care service] quite separate because we really need to be concluding our involvement within a three to four month period. Clearly that's going to be missing out on a whole lot of potential issues that could arise."* (Psychosocial Support Services Manager, community service)

As none of the services had a dedicated bereavement staff member, follow-up fell to various team members as an additional role. Chaplains conducted the bereavement care at the in-patient unit, and it was the role of the social worker at the consultancy service. Counsellors at one community service (the only service with a counselling team), tracked bereavement care with people who had been identified as needing follow-up using the Bereavement Risk Index (BRI), a staff-completed observational checklist [56]. At the other community service, bereavement follow-up was conducted predominantly by nursing staff. Follow-up at other services was based on telephone calls and individual circumstances. The lack of a dedicated staff member to take responsibility for bereavement care contributed to inconsistency in follow-up contact:

*"...so up 'til now the BRI [Bereavement Risk Index] process has essentially been nurse led. Something that we're just pushing through at the moment is that where a counsellor is involved with the person pre-death, it's the counsellor's job to drive the bereavement process."* (Psychosocial Support Services Manager, community service)

*"You mark it in the diary that it is designated to all the team, you know 'this bereavement call is due on this day'."* (Clinical Nurse Manager, community service)

The length of time spent in maintaining these tenuous links with bereaved former caregivers also varied between services "...from three or four calls" as indicated by the Chaplain from the inpatient unit to 12 months post-

death at the consultancy service. The Psychosocial Support Service Manager from the community service said: *"We really need to be concluding our involvement within a sort of 3 to 4 month period."*

The focus of palliative care is on patient care in the pre-death period, which poses challenges for staff's support of family caregivers:

*"...particularly where you know the service has basically withdrawn to a large extent. This is probably the last, if the only remnant of the services from [name of service]... it's a full blown service while the person is alive and being cared for in palliative care, but now it's just down to one person contacting over the 'phone. So it's diminished in that regard."* (Counsellor, community service)

Typically, follow-up by all the services included telephone calls, a remembrance card at 12 months, and an invitation to a memorial service, rather than assessment of support needs:

*"We send a card, then we have a service. The most contact we have from carers is from our annual remembrance card and it's amazing the number of times we get a phone call back after that, or a card to say 'we can't believe you actually remembered' the person."* (Clinical Nurse Manager, community service)

### Logistics of maintaining contact with former caregivers

Most services do not have face-to-face contact with bereaved caregivers following the patient's death which raised a number of problems. A measure comprising a number of items, with a variety of responses, would be very difficult to complete by telephone. While all participants agreed that a more structured assessment would be helpful, a self-report measure would not be feasible in the weeks or months following a death:

*"I looked at all of them [grief self-report measures] and I found them all very difficult to be able to use over the 'phone. I guess the only thing for us [government community service] it would perhaps mean we would need to re-think the way we do our bereavement [support], and for the first month instead of 'phone contact make a visit to make it a workable thing."* (Clinical Nurse Manager, community service)

Bereaved former caregivers could be difficult to contact after the patient's death:

*"Some of those demographic details, and conditions of people, their lives may have changed. They may have changed address for example."* (Counsellor, community service)

Follow-up contact was also time-consuming and often overlooked when bereaved former caregivers were not answering calls:

*"You make a 'phone call, you can't get through. The following day you make a 'phone call, but unfortunately the busy-ness of people that are still with us, then those 'phone calls get lost along the way, and beneath the week, you mark it in the diary that it is designated to all the team, you know 'this bereavement call is due on this day'. If you've done it perhaps three times, we don't then follow it up. If you've missed somebody three times, we go 'okay we'll go to the next month', so there is actually no way of finding out perhaps if a carer is okay, or not okay. It just gets lost I think in the busy-ness of how we are."* (Clinical Nurse Manager, community service)

#### Gatekeeping

Palliative care teams are reluctant to refer caregivers on, preferring to support them within the team:

*"I think it's very natural in palliative care teams to follow-up, well initially, but that sense of being able to hand over to a formal structured bereavement service... for people falling outside the normal is, I think, something that we probably in palliative care have been guilty of retaining ownership of...it's very hard for us to not let go of the fact that we should be doing something...there are times we shouldn't be doing anything."* (Physician, in-patient unit)

While all services provided some follow-up of bereaved former caregivers identified as being at potential risk of poor bereavement outcomes at multidisciplinary team meetings, this was often based on intuition as to whether follow-up should proceed. As the Clinical Nurse Manager from the community service said: *"...it's very much a gut feeling, or when you make a phone call to that person, how they respond I guess."*

#### The way forward

Because existing instruments were found unsuitable for use in an assessment model, the Physician from the in-patient unit stated: *"Can I recommend that you make a new one [measure]?"* The participants suggested that a measure be constructed that could be tailored for use in palliative care, prior to the patient's death in order to assess the caregiver's bereavement risk.

A new measure should be brief and easy for caregivers to use, simple for staff processing and documentation, and would ideally account for the known risk factors for poor bereavement outcomes. As the Clinical Nurse Manager from the community service said, *"bereavement stuff, for it to be consistently used we need something simple. If*

*it's a big piece of paper we're not going to do it. We're going to put it down to the bottom of the pile."* The Clinical Psychologist suggested focusing on *"...the main risk factors for bereavement. Whether its previous mental health sort of diagnosis, where there are low levels of social support, low economic, you know, low SES [socioeconomic status], all those sorts of things."*

#### Discussion

While the different disciplines and service models of care varied between the reference group members, their data formed a cohesive explanation of the barriers to bereavement risk assessment in palliative care [43]. None of the 12 self-report measures was considered to be suitable for use in palliative care; as such, the initial aim to select existing grief measures for use in a bereavement risk assessment model was not achieved. When considering bereavement risk assessment, the participants highlighted several barriers to the use of existing measures in their services. Specifically, they described the ways in which systems of care, logistics in relation to contact with former caregivers, and conflation between caregiver stress, burden and grief affects the ability to assess caregiver grief. The specific barriers changed between the pre-death and post-death period. The issues in the pre-death period largely centred on staff's reluctance to ask intrusive or sensitive questions as end-of-life approached. In the post-death period, contact with caregivers was difficult due to various barriers such as staffing, funding, and availability of contact with caregivers.

#### Pre-death assessment

In spite of the many challenges to assessment before the patient's death, this period presented the best opportunity for services to assess caregiver bereavement risk because caregivers have face-to-face contact with staff. As in findings by Agnew et al. [18], the health professional participants described flaws in the current use of staff-completed checklists where the checklists are generally completed following the patient's death with information that is often based on staff intuition. Therefore, the participants highlighted the need to develop a new measure that would include known risk factors for complicated or prolonged grief, yet be brief and user-friendly for both caregivers and palliative care service use. If a more robust assessment of caregiver bereavement risk could be achieved at this time caregivers could be provided with assistance tailored to their needs [27]. This project has identified the hurdles to be overcome, so that this aim can be achieved.

Palliative care service models will no doubt continue to vary due to the nature of the service and their funding. As such, patients (and their caregivers) will continue to move between services within the system. A standardised bereavement risk assessment protocol, transferrable across



services, would be beneficial for both caregivers and staff in order to identify caregiver bereavement needs in a timely manner, thus minimising duplication in assessment and the provision of support, and reduce the likelihood of caregivers being missed between the various services in the system. While staff focus and palliative care resources remain primarily on patient care in the lead-up to the patient's death [57], the development and use of a validated brief caregiver self-report measure could enable staff to continue patient care with more assurance that family caregivers' emotional needs are being met, whilst ensuring that caregivers' issues are not a distraction from patient focused care. Standardised assessment across the palliative care trajectory should also have the added benefit of tracking change for caregivers across time, and more readily identify which of the available palliative care services might be best placed to provide support.

The introduction of a new measure may also alleviate the problems related to staff gatekeeping where decisions on the allocation of support are based on staff preference to intuit caregiver needs rather than asking caregivers to report their needs. The Carer Support Needs Assessment Tool (CSNAT), which asks caregivers to state their needs, has provided structure and guidance to previously undocumented, informal conversations [57]. In Australia [58] and the United Kingdom [59] caregivers identified that dealing with their feelings and worries was in the top three of their needs, indicating that the avoidance of directly assessing caregivers' needs and distress is contrary to what caregivers themselves want. This formal identification of caregiver concerns led to early intervention, and resulted in positive outcomes for caregivers in reducing caregiver strain. Similarly a self-report measure of bereavement risk may allow caregivers to voice their feelings and worries without staff discomfort about having sensitive conversations.

The reference group health professionals stated that the multidisciplinary teams are well able to build a comprehensive picture of families' needs during the palliative care trajectory. While this is a legitimate and valuable method of assessment, the addition of a caregiver self-report would move towards a caregiver-led [57], person-centred approach, rather than the present paternalistic model based on 'expert' judgement and observation of caregiver responses. It should also move away from the present practice of staff observation and discussion that is undertaken without caregiver knowledge or consent [21]. A caregiver self-report measure could empower caregivers and assist palliative care staff to intervene where appropriate. Assessment to identify those at risk of complicated or prolonged grief, and referral where required, needs to become standard practice to circumvent potential ongoing mental health issues [60, 61]. Boerner, Mancini, and Bonanno [61] advocate that health professionals are

ideally placed to gather such information prior to a death and address the issues by referring those at elevated risk to clinicians or services who may provide appropriate support in a timely manner.

The reluctance to address caregiver emotional needs directly may stem from misunderstandings by health professionals about the grieving process. Powazki et al. [62] found that education for nurses relating to end-of-life care and communication was lacking. Surveys of university courses also reflect a similar lack of education that would prepare health professionals across disciplines to provide grief support [63]. General Practitioners also tend to try and resolve patients' grief themselves using psychotherapeutic strategies without the specialist training required [64]. Such lack of understanding by health professionals in relation to grief may account for the belief by reference group participants that they should 'do something' for the majority who do not need anything other than the support of family and friends.

Findings support previous research suggesting that palliative care multidisciplinary team members often believe they are best placed to provide psychosocial support, and indicate that there is a reluctance to refer to appropriate support services [65]. A caregiver self-report measure of bereavement risk may clarify for staff when referral is needed, accompanied by a referral pathway to appropriate support. However, education will be needed to encourage staff to incorporate such assessment and sensitive conversations into routine practice. Education about all aspects of grief, particularly in relation to staff judgements and intuition about caregivers' emotional responses, needs to occur across the gamut from university education to professional development programs [62].

#### Post-death assessment

For the period following the patient's death, both in the short term and longer term, the greatest challenges to bereavement risk assessment stem from logistical barriers in maintaining contact with former caregivers. The participants believed that existing self-report measures would be too long and complex to administer via telephone, given this was generally the only means of contacting caregivers. Even if services had staff trained in assessment and dedicated to bereavement care, the data from this study suggest the availability of appropriate bereavement services and referral pathways is lacking. This issue could be addressed by establishing referral pathways to appropriate community services [64]. As Rumbold and Aoun [66] suggest, palliative care services would do well to forge connections with community services that could meet the needs of this group so as to minimise the possibility of their developing ongoing health issues.

Likewise, the use of a prolonged grief measure at six months following the patient's death, as per bereavement standards [20], also proved challenging. The DSM-5 states a 12 month period should elapse before bereavement related criteria can be met. However, for those with comorbid depressive diagnoses, bereavement has been removed as an exclusion to treatment, allowing this group to receive help sooner rather than later [67]. Research indicates that caregivers are at higher risk of depressive symptomatology with many meeting clinically significant criteria in need of assistance [68, 69], adding weight to the argument for earlier, more robust assessment to identify those in need of follow-up to prevent ongoing health issues.

#### Bridging policy and practice

Bereavement support standards for specialist palliative care services [20] have only recently been developed and, as such, have provided an initial, much needed framework to address the many complexities of bereavement care. The standards recommend that universal strategies such as screening and risk assessment, and supportive programs and information should be extended to all caregivers across the palliative care trajectory. Specialist bereavement support strategies including counselling and psychotherapy and/or bereavement support groups should be offered to those currently distressed or at elevated risk of complex grief related issues. This protocol is supported by the public health model [27] articulating three tiers of need.

In the United States of America, hospices are required by medical insurance funders to provide assessment of needs in relation to bereavement care for approximately 12 months following a patient's death [70]. While this is not yet current practice in Australia it is becoming increasingly likely that it may become so. Accreditation for health services, including hospitals and palliative care services, is already linked to compliance with standards [71] with funding expected to be linked in the foreseeable future [72]. Should these conditions be required, palliative care services will need to address bereavement risk assessment as a matter of greater priority than has already been proposed [73].

#### Strengths, limitations and future research

These stakeholder group discussions provide a data-driven explanation of the issues affecting bereavement risk assessment practice in a variety of palliative care service settings. The strength of this study was the composition of the reference group. There was a diversity of health professional designations typical of a multidisciplinary palliative care team, as well as a bereaved former caregiver. This diversity facilitated an opportunity for various perspectives on data collected in relation to the research question, which increases the study's capacity to inform practice

[43]. A greater number of people in the reference group, including more bereaved former caregivers, may have added diversity to the opinions in the group, but may also have decreased the opportunity for all members to contribute. Given the specific focus of the group, the number of participants was chosen to optimise the involvement of all participants [74, 75]. Nevertheless, the findings may not transfer to other locations with different palliative care service models although research shows that similar challenges to bereavement care exist in other developed countries [23]. Due to the many difficulties with post-death assessment highlighted by the reference group future research should focus on the development and testing of a pre-death measure of bereavement risk that is feasible for palliative care settings, particularly given the consequences this minority of individuals face in terms of poor health [7]. If a measure could assess for the risk factors in complications of bereavement and predictors of bereavement outcomes, then palliative care service providers could refer caregivers at elevated risk to appropriate health professionals or services for appropriate monitoring and support [61].

#### Conclusion

The broad aim of this study was to develop a bereavement risk assessment model using existing measures that would be congruent with bereavement support standards [20]. The phase of the overall study reported in this paper examined the measures in collaboration with a reference group of palliative care stakeholders via a series of group interviews. However, existing measures were found to be unsuitable. A number of barriers will need to be overcome before assessment can become routine practice. The barriers are associated with system of care issues, such as multiple service use and availability of support personnel; and logistics relating to service contact with caregivers, where contact following the patient's death is difficult due to funding and problems with telephone contact. Staff gatekeeping, where follow-up support is often determined through intuition, as well as conflation between caregiver stress, burden and grief were also identified as problematic in risk assessment.

We recommend the development of a brief caregiver self-report measure of bereavement risk to allow caregivers to voice their worries and concerns [59] allowing staff to remain focused on patient care. This may reduce burden on both staff and palliative care services. Comprehensive assessment of caregiver bereavement risk may more readily ascertain the type of support a bereaved former caregiver may need, thus allowing palliative care services to provide appropriate support or referral to other organisations specialising in bereavement support [66].



## Abbreviations

BGQ: Brief Grief Questionnaire; BRI: Bereavement Risk Index; CBI: Core Bereavement Items; CG: Complicated grief; CSNAT: Carer Support Needs Assessment Tool; DSM-5: Diagnostic and statistical manual of mental disorders-5 (5<sup>th</sup> Edition); GEM: Grief Evaluation Measure; HGRC: Hogan Grief Reaction Checklist; ICG: Inventory of Complicated Grief; ICG-R: Inventory of Complicated Grief Revised; MM-CGI: Marwit-Meuser-Caregiver Grief Inventory; PG-12: Prolonged Grief-12; PG-13: Prolonged Grief-13; PGD: Prolonged Grief Disorder; PTSD: Posttraumatic Stress Disorder; SES: Socioeconomic status; TRIG: Texas Revised Inventory of Grief; TTBQ: Two-track Bereavement Questionnaire.

## Competing interests

The authors declare that they have no competing interests.

## Authors' contributions

MS: Participated in the conception and design of the study, performed study procedures and collection of data, analysis of data, and drafted and edited the manuscript. MO: Participated in the conception and design of the study, analysis of data, helped with the drafts and editing of the manuscript, and final approval. SA: Participated in the conception and design of the study, analysis of data, helped with the drafts and editing of the manuscript, and final approval. LB: Participated in the conception and design of the study, analysis of data, helped with the drafts and editing of the manuscript, and final approval. All authors read and approved the final manuscript.

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## **CHAPTER SIX**

### **Development of a Brief Grief Measure**

“We cannot do everything at once, but we can do something at once.”

- Calvin Coolidge

#### **Chapter Overview**

The response to the findings from the first two phases of the study is outlined in Chapter Six. Responding to stakeholder recommendations and needs is characteristic of action research (Hockley et al., 2013). Phase one identified existing measures for potential use in a bereavement risk assessment model as outlined in Chapter Four. Phase two involved collaboration with a reference group of palliative care stakeholders to develop the model; however, the group found that existing measures were unsuitable for use. As discussed in Chapter Five, reference group health professionals recommended that a new measure be developed, centred on risk factors for prolonged or complicated grief, to provide useful screening information for the palliative care services that chose to adopt it.

The aim of this third phase of the study was to develop a self-administered caregiver grief measure, suitable for use in palliative care settings prior to the patient's death. In this chapter, the step-by-step development of the measure is outlined in the attempt to bridge policy and practice. The chapter begins with findings from grief and bereavement literature in relation to risk factors for complicated or prolonged grief. The chapter concludes with an account of a small pilot study to test the measure's clinical utility in three models of palliative care: a community based domiciliary service; an in-patient unit; and a consultative service in an acute teaching hospital. The chapter details the development of the measure which occurred in collaboration with an advisory group of grief service providers and bereaved former caregivers who reviewed the items across four drafts of the measure. The final version of the measure, including instructions and rating of items, is also described.

## **Introduction**

In phase two of this study, the reference group health professionals indicated their preference to observe family caregiver interactions and behaviour emphasising the need for caregiver self-report questionnaires. Self-report methods would offer more reliable data on caregiver cognitive and emotional states than observation by staff (Groth-Marnat, 2009 ; Osberg, 1989). Self-report assessment is also congruent with a person-centred, or a partnering with consumers approach to care, which is regarded as a marker of quality health care by Australian government health care standards (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011). Such assessment has become policy in many developed nations (Bell, 2013). Given the high burden of care for palliative care caregivers, it is anticipated that the opportunity to express caregiver concerns and needs will result in timely support, and ultimately lead to improved health outcomes (M. Stroebe & Boerner, 2015).

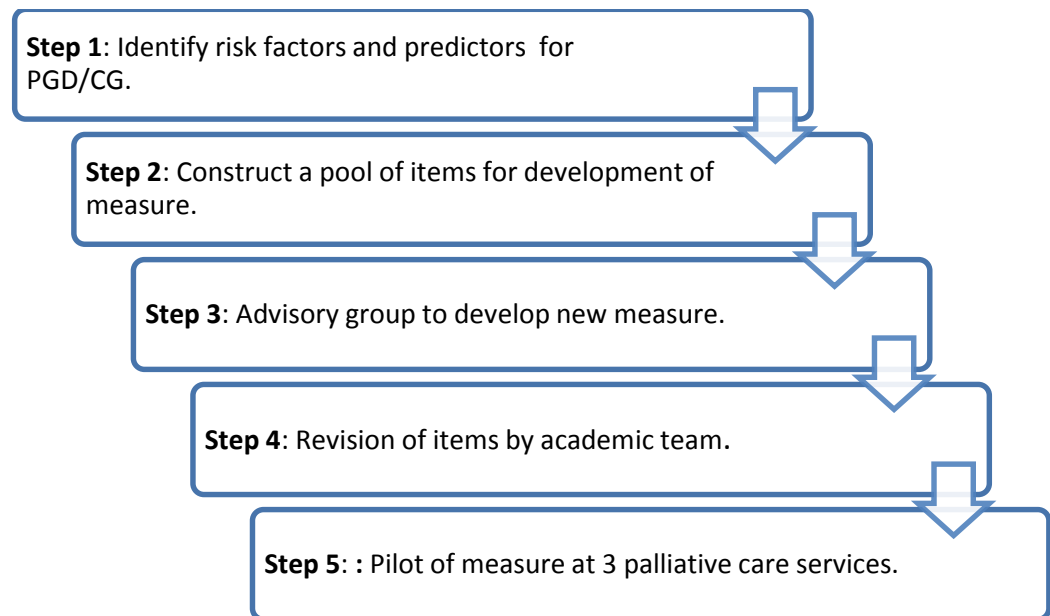
The intention behind developing the new measure was to screen caregivers prior to the patient's death when they are in contact with the palliative care service, rather than after the death when there is limited contact with the service. The aim of screening prior to the death is to identify those caregivers who are potentially in the elevated risk categories for complicated or prolonged grief in accordance with the public health model of bereavement support (Aoun, Breen, et al., 2012) discussed in Chapter Two. An important consideration in developing a self-report measure is that the measure will need to be brief enough to be acceptable to caregivers as they care for the patient in the approach to end-of-life, and to be applicable and feasible in a busy clinical setting.

The terms complicated grief (Shear et al., 2005) and prolonged grief (Prigerson et al., 2009) are used interchangeably in this chapter for the purposes of describing the situation of the minority of bereaved individuals who are potentially at risk of poor bereavement outcomes (Zisook & Shear, 2009).

## **Development of a Measure of Caregiver Grief for use in Palliative Care**

The development of the new measure was undertaken in a series of five steps (see Figure 6.1, p. 89). In step one, a published systematic review of risk factors for complicated grief (Lobb et al., 2010) was used to build a comprehensive list of risk

factors and predictors of prolonged or complicated grief to correspond with items on the measure. In step two, a pool of items was derived from existing measures to match the risk factors and predictors identified in step one. In step three, an initial measure comprising 20 items with a broad coverage of risk factors was constructed using items from the pool of items developed in step two. An advisory group was formed comprising bereaved former caregivers and bereavement service providers, to collaboratively develop the measure from the pool of items. This process was iterative across various drafts and continued until the service provider members were satisfied that the items would capture information that may indicate a caregiver would not adjust easily following the death of the patient. In step four, the measure was reviewed by an academic team of bereavement and palliative care researchers to ensure theoretical relevance, clarity, and parsimony of wording of the items. In step five the measure was piloted and evaluated in three service models of palliative care - a community based domiciliary service, an in-patient unit, and a consultative service in an acute teaching hospital.



*Figure 6.1 Steps to develop a brief grief measure*

### **Step one: Identification of Predictors and Risk Factors.**

A list of predictors or risk factors associated with complicated or prolonged grief was drawn up based on a systematic review of empirical studies relating to predictors of complicated grief (Lobb et al., 2010). This is the sole systematic review of risk factors and predictors for complicated grief identified at the commencement of this phase of the study; undertaken between March and September 2014. The systematic review was based on a hierarchy of evidence for quality of literature used along with quality of research in terms of sample sizes and assessment measures. A risk factor relating to grief and bereavement is defined as a behavioural, lifestyle or environmental attribute to which one may be exposed, that is associated with a certain condition or outcome that may be preventable (W. Stroebe & Schut, 2010). In the review by Lobb and colleagues, complicated grief was defined as "...a pattern of adaptation to bereavement that involves the presentation of certain grief-related symptoms at a time beyond that which is considered adaptive" (Lobb et al., 2010, p. 674).

The risk factors and predictors of prolonged and complicated grief for this present study were grouped into different categories than those in the Lobb and colleagues (2010) systematic review which included, for example, childhood and dependency factors as well as caregiving and traumatic death. Reasons for altering these categories were to remove some background factors that are difficult to assess by palliative care staff. Taking into account other risk factor literature, six broad domains were formulated for the present study: 1) relational/interpersonal; 2) cognitive processing; 3) dispositional/personality/coping and resilience; 4) spiritual/religious and meaning-making; 5) previous or comorbid mental health issues; and 6) situational factors (encompassing environmental, instrumental, and social domains). These are shown in Table 6.1 on page 91.



Table 6.1

*Risk Factors and Predictors of Poor Bereavement Outcomes*

<b><i>Relational and interpersonal risk factors</i></b>
Attachment style, separation distress/anxiety
Previous adversities, prior losses/deaths
Dependency on the patient
Perceived emotional and instrumental support from family and friends
<b><i>Cognitive risk factors and predictors</i></b>
Depressive/negative rumination/repetitive thinking (particularly injustice/relationship)
Anxious worry/negative thinking, view of self, of life, of future
Avoidance and/or intrusive thoughts
<b><i>Dispositional, resilience and coping factors</i></b>
Trait dependency
Neuroticism
Trait anxiety
Pessimistic worldview versus optimism
<b><i>Spiritual/religious, meaning and worldview factors</i></b>
Faith community as a supportive network
Challenge to self-narrative
Loss of meaning
<b><i>Mental health risk factors</i></b>
Pre-existing or co-morbid mental health issues/diagnoses
Substance use (drug/alcohol/medication)
Sleep disturbance/insomnia
<b><i>Environmental, situational, instrumental risk factors</i></b>
Caregiver burden
Patient care and circumstance during the episode of care and end-of-life
Concurrent stressful events
Financial resources
Preparedness for the death (instrumental and informational)
Practical support

**Relational factors.** Individuals with insecure attachment styles, and in particular those who have experienced adversities that create separation anxiety during childhood, are at elevated risk of complicated grief during bereavement in adulthood (Silverman, Johnson, & Prigerson, 2001). Those with anxious-ambivalent attachment will be more likely to have complicated grief reactions that do not remit over time, while those with avoidant attachment could be expected to exhibit a seeming lack of grief response, and are more likely to report somatic symptoms (Wayment &

Vierthaler, 2002). Fraley and Bonanno (2004) suggest avoidant attachment may be further defined as either fearful or dismissing avoidance, with the later more likely associated with resilient responses, where an individual directs attention away from threats to his/her sense of self and autonomy. Higher dependency on the deceased is also associated with complex grief responses and increased risk of mental and physical health illnesses, particularly depression and suicidality (Johnson, Vanderwerker, Bornstein, Zhang, & Prigerson, 2006; Thomas et al., 2014). Findings on the association between conflictual spousal relationships and increased risk of complicated grief have been mixed, with some studies showing that supportive spousal relationships may be more likely to result in complicated grief for the bereaved spouse (Lobb et al., 2010). Previous and multiple other losses and deaths are also risk factors for complicated grief responses (Gamino, Sewell, & Easterling, 2000; Love, 2007).

**Cognitive risk factors and predictors of complicated grief.** Depressive rumination; that is, repetitive constant thinking about negative feelings (Eisma et al., 2014) is associated with depressive mental health disorders post-loss, and is a strong predictor of complicated grief reactions. Eisma and colleagues found that rumination about injustice and relationships connected to the loss tended to be linked with complicated grief symptoms. Boelen, van den Bout, and van den Hout (2006) suggested that those who hold negative views of self, their life and their future, are more prone to dwell on the loss. Such thinking may impede healthy integration of the loss, especially when the individual believes that she/he will be unable to make the necessary adjustments to life without the deceased. Furthermore, it is possible that these individuals may interpret the pain of the loss as being abnormally severe, leading to further counterproductive efforts to control their feelings and thoughts. Such negative thinking may also lead to behaviour such as the avoidance of places, people and activities that are reminders of their loss, which, in turn, further hampers recovery. Findings from the Boelen, van den Bout, and van den Hout studies found that negative cognitions in relation to self, (for example, “My life has no meaning since my partner’s death”) were associated with complicated grief and depression. However, avoidance, while associated with symptoms, was only predictive of depression at 16 to 19 months post-loss.

**Dispositional, resilience and coping factors.** Dependency as a personality variable is associated with more difficult adjustment post-loss (Bonanno et al., 2002).

However, dependency as a construct is somewhat vague, possibly because of its multifaceted nature (Morgan & Clark, 2010). Dependency is broadly defined by the authors as a need to have physical and emotional proximity to another, and is typified by an individual's focus on the needs of the other, as well as requiring approval from the other. Morgan and Clark noted that dependency is often implicated in mental health disorders such as phobias or eating disorders. There is evidence to suggest that personality traits such as neuroticism and trait anxiety also play a role in complicated grief responses (Thomas et al., 2014). Neuroticism typically features insecurity and worry (McCrae & Costa, 1987). Tomarken and colleagues (2008) found that a caregiver's pessimistic world view was an important pre-death predictor of complicated grief. On the other hand, positive, optimistic individuals report fewer of the complicated or prolonged grief symptoms associated with poor bereavement outcomes (Hudson, Thomas, et al., 2011; Riley, LaMontagne, Hepworth, & Murphy, 2007). Optimistic individuals appear to cope differently; they approach events with flexibility, and are more inclined to take direct action to solve problems and seek social support. They are more accepting of their circumstances, have belief in a world that is just, and are therefore more resilient. Conversely, those lacking confidence in their ability to cope with stressful events, such as the death of a family member, tend to believe that negative events are outside their control and are more likely to engage in maladaptive coping responses (Bonanno et al., 2002). As mentioned previously, Burke and Neimeyer (2013) assert that given the wide variety of grief-related responses by bereaved people, greater distress lies at one end of a continuum with resilience at the other.

**Religion, spirituality, worldview and meaning.** It is possible that spiritual or religious beliefs help individuals make meaning of their situation, or that such participation offers a support network and community, which is protective against poor bereavement outcomes (W. Stroebe & Schut, 2010). However, results from studies on the association between complicated grief responses and religious or spiritual beliefs are mixed (Burke & Neimeyer, 2013). Neimeyer (2014) holds that the death of a significant other can challenge the bereaved person's self-narrative that organises and shapes their world and connects past, present and future. Those who are resilient tend to cope with the reconstruction of their self-narrative, while those who lack adaptive coping skills struggle with the meaning of the loss in terms of their own self-narrative

and are at greater risk of complex grief issues. Deaths that challenge one's worldview, such as the death of a child or deaths from violent or unexpected causes can leave many people struggling to make sense of their loss. In looking at the psychological profile of family caregivers caring for a palliative care patient, Hudson and colleagues (2011) found that almost half (44%) of these individuals were likely to have comorbid anxiety or depression, with 15% meeting criteria for grief prior to the death of the patient, and 10% reporting substantial levels of demoralisation. The demoralisation was related to loss of meaning, loss of hope regarding the future, and was almost certainly accompanied by financial problems and sleeplessness. The caregivers in this study were more likely to: be women, have poor health, and live with the dying patient, who was in all probability a spouse.

**Previous or comorbid mental health factors.** Grief responses can be intensified in those individuals with co-morbid mental health diagnoses (Lichtenthal, Cruess, & Prigerson, 2004; Love, 2007; Thomas et al., 2014). It is also common for caregivers, who have cared for and supported a loved one with a terminal illness, to experience depression and/or anxiety prior to the death (Tomarken et al., 2008). In an Australian study, 44% of palliative care family caregivers who were screened for anxiety and depressive disorders, rated higher than the cut-off scores for anxiety and depression, with 15% meeting criteria for pre-loss grief (Hudson, Thomas, et al., 2011; Thomas et al., 2014). Drug and alcohol use and sleep disturbances, while not distinctive features of complicated grief, may reflect coping or mental health responses and, as such, can be indicators of emotional distress (Jordan, Baker, Matteis, Rosenthal, & Ware, 2005).

**Environmental, situational, instrumental risk factors.** Women generally seem to be at higher risk of complicated grief responses than men, and tend to have more severe grief symptoms (Boelen et al., 2006). Caregiver burden throughout the patient's illness also increases the risk of prolonged or complicated grief, given the high emotional toll and fatigue caring entails (Kelly et al., 1999; Lai et al., 2014). Factors relating to delivery of patient care, such as grievances about the quality of patient care and/or caregiving burden during the palliative care and end-of-life period, can also influence bereavement outcomes (Thomas et al., 2014). Concurrent stressful life events during the patient's illness and severity of the patient's condition at the time of referral to palliative care, have also been found to contribute to poor adjustment

post-loss, indicating that later referral to palliative care may be linked to poorer bereavement outcomes (Kelly et al., 1999; Tomarken et al., 2008). Perceived lack of practical support is also associated with poorer outcomes for caregivers (Kelly et al., 1999; Thomas et al., 2014) and lack of financial resources may be a secondary stressor thus further contributing to difficulties with adjusting to the loss (Thomas et al., 2014; van der Houwen et al., 2010). In terms of protective factors, being prepared for the impending death is linked with better bereavement outcomes (Barry, Kasl, & Prigerson, 2002; Schulz, Boerner, Klinger, & Rosen, 2015). Schulz and colleagues suggest that preparedness for the death is likely to be multidimensional, involving emotional, practical and informational elements, and that dependency on the deceased may also play a role in caregiver preparedness.

**Framework of understanding grief responses.** The Dual Process Model (M. Stroebe & Schut, 1999), discussed in Chapter Two, offers a valuable framework to understand the ways in which people cope with their losses. Understanding how the various risk factors and predictors for complicated grief as stressors are dealt with in relation to resources allows health professionals to plan for problem-solving or emotional-focused approaches to support those caregivers at elevated risk of complicated or prolonged grief (Tomarken et al., 2008). An assessment of the presence of risk factors and predictors of prolonged or complicated grief in palliative care caregivers should therefore assist health professionals to understand a caregiver's potential to be at risk of poor bereavement outcomes following the death of the patient, and indicate the type of assistance that might best suit the individual.

**Step two: Construction of a Pool of Items** (Refer Appendix D for pool of items).

Existing measures identified in the grief and bereavement literature (Sealey, Breen, et al., 2015) were perused for questions and statements that would fit the risk factor and predictor domains of prolonged or complicated grief as outlined in step one. Any relevant items from the measures were matched to the risk factor and predictor categories. Many of the risk factor domains overlap, for example, neuroticism as a trait features worry (McCrae & Costa, 1987) and is therefore also in the domain of cognitive processing, and financial concerns may also involve rumination and cognitive processing. Because the measure is intended for use prior to the patient's death, the wording on the majority of items was modified, and terminology amended to

suit Australian vernacular. The content of items for the six risk factor and predictor domains are outlined in Table 6.2 (see page 97).

### **Step three: Collaboration with an Advisory Group to Construct Measure**

In order to develop a brief measure with clinical utility and acceptability to caregivers, an advisory group of bereavement service health professionals and bereaved former caregivers was formed to guide the selection of risk factor items appropriate for the measure. The aim of consulting with the bereavement service providers was to gain information about each of the items in relation to whether an item might deliver clinical information needed to identify those caregivers who might potentially be in the moderate or elevated risk categories, in accordance with the public health model, following the patient's death. The aim of consulting with the bereaved former caregivers was to ensure that the wording of the items was understandable and acceptable to caregivers in order for the measure to have utility in a clinical setting

Table 6.2

*Content of Items for the Risk Factor and Predictor Domains*

<b>Risk factor domain</b>	<b>Number of items</b>	<b>Content of items</b>
Relational Interpersonal	13	Dependency on the patient (emotional and instrumental); extent of support/dependency; family communication styles; perceived support; connection with others.
Cognitive	14	Patterns of worry/rumination; feelings of confusion and uncertainty; effect thinking has on activities; negative outlook; self-blame; thoughts of avoidance and intrusion.
Dispositional, resilience, coping	7	Beliefs about coping; discovering personal resources; history of overcoming problems; belief about the future.
Spiritual/religious, worldview and meaning	5	Degree to which beliefs and values are supportive; faith in a higher power; feelings of meaninglessness and emptiness; feelings of being at peace.
Mental health	7	Suicidal ideation; physiological symptoms of anxiety and panic; feelings of anxiety and fear; use of alcohol/substance use to cope; sleep patterns.
Environmental, situational, instrumental	9	Consequences of caregiving/caregiver burden; physical health status; physical wellbeing; financial problems; preparedness for the death/acceptance of the situation; perceived support from friends/family.

## Method

**Study Design.** In-depth interviewing of the participants was chosen as the optimal method to examine each of the items in detail as to its application for clinical use as the topic under scrutiny was directed specifically towards choosing individual items most appropriate for the measure. Low-structure interviewing was adopted so as not to restrict participants' expansion on the issues relating to each of the items. Such

interviews are valuable where a specific topic needs focus in relation to the perspectives of particular individuals, and provides both explanatory and descriptive information (Hesse-Biber & Leavy, 2011).

***Participants.*** The eight advisory group participants were women ( $M_{age} = 56.1$  years, age range: 49-64 years). The bereavement service provider participants were recruited from palliative care services and private practice; three were registered counselling psychologists (one in private practice, two worked in a private hospital clinic contracted to a hospice for bereavement care); two were counsellors in private practice; one was a licensed clinical social worker (now in private practice but she had previous palliative care experience); and two were bereaved former caregivers who also engaged in voluntary palliative care work. Years of experience in counselling grief and loss for the six bereavement service providers ranged between four and 15 years (Median 6 years); four had palliative care experience. The bereaved former caregivers had both cared for their husbands who had died three and four years previously, one from motor neurone disease, one from melanoma. One woman had also cared for her sister-in-law and brother prior to their deaths some three or four years prior to her husband's death. As such, both women had extensive contact with the medical system and palliative care services as caregivers.

### ***Materials and Procedure***

***Recruitment.*** Palliative care services providing counselling support, psychologists, and counsellors in private practice specialising in grief counselling in metropolitan Perth, were contacted via email to gather expressions of interest for people to participate in the advisory group. The bereaved former caregiver from the reference group was also contacted as she had previously expressed interest in further participation in the study; this provided continuity. This former caregiver referred another bereaved former caregiver who had expressed interest in the research.

***The measure.*** Twenty items were chosen for the measure so that a caregiver, caring for a patient towards end-of-life, would be more likely to be able to complete a brief questionnaire. The items were also chosen to cover broadly the risk factor categories identified in the literature as outlined above, rather than concentrate around a limited number of risk factors. At the end of the 20 items, an open-ended question



asked caregivers to describe factors (if any) that might affect their ability to care for themselves or others over the coming weeks.

*Developing the measure: the process.* The interview process involved iterative one-on-one interviews which were conducted over a three month period, although two counselling psychologists were interviewed together as it was their preference to conduct the interview at their workplace to minimize the impact to client scheduling. Following an explanation of the aim of the interview, each participant was given a copy of the sample measure under scrutiny, and was asked to comment on each item in turn. Interviews ranged from 30 minutes with the bereaved former caregivers, to just over one hour with the counsellors (Mean 48.02 minutes). During each interview the items on the measure were examined individually, and, if advisory group members believed that an item was unsuitable, it was removed, and substituted with another item from the pool of items, until the final draft was deemed satisfactory for piloting. Four drafts of the measure (samples A to D) were scrutinised by the advisory group members. (Refer to Appendix E for a comparison of the four drafts of the measure).

*Data collection and analysis.* In accordance with Braun and Clarke's (2006) thematic analysis each interview was digitally recorded and transcribed verbatim prior to the next interview so that any comments regarding an item could be specifically probed during the subsequent interview. The recordings were repeatedly listened to by the researcher in order to become familiar with the content. Comments made in relation to each item were summarised into a table format, and were categorised as being affirmative or non-affirmative of an item's construct in relation to utility in clinical assessment. If data collected from the participants suggested an item would not be clinically useful, the item was removed and substituted with another item. Data collection was an iterative process of systematically working through items until comments on each of the items were positive in affirming the items application.

## **Results**

*Findings by Advisory Group.* The process commenced with the bereaved former caregivers being asked to view the initial draft (sample A) to gauge their responses to the items prior to scrutiny by the clinicians. Both bereaved former caregivers expressed similar responses to and attitudes towards the items. There was confusion in relation to two items that aimed to assess the degree to which a caregiver

might be practically and/or emotionally dependant on the patient. Item two stated “[the patient’s name] has been a major source of emotional support to me”, and item three asked “how dependent are you on [the patient’s name] in general?” Both caregivers said that, as their husbands had been ill for some time prior to death, they as caregivers were providing support to their husbands, rather than their husbands providing support to them. As such, they both asked for clarity in relation to the meaning of these questions. They admitted that they were still able to ‘talk things over’ with their husbands, about making financial decisions for example, during the earlier stages of the illness, and this was of comfort and support to them, and something they missed as the disease progressed. They talked through several possible scenarios to describe how situations may differ. For example, one caregiver said that she was not at all dependent, either emotionally or physically, on her daughter for example, but would “be absolutely devastated if anything happened to her” and, as such, the items would not capture information about the depth of a relationship. They suggested clarifying item two by adding “I talk things over with him or her,” and adding “in a practical sense” to item three.

The caregivers were also asked about how they would emotionally respond to completing the measure as a caregiver. Overall, they both believed the measure was a positive step in that it would give caregivers a voice, would reassure them that someone was concerned about them, and would help caregivers feel that they mattered. Both said the item relating to suicidal ideation was not distressing, and expressed feelings of comfort and reassurance about being asked a question that would indicate that the service was concerned about their wellbeing. One caregiver suggested not adding more items to the existing 20. The other caregiver suggested adding an item that related to financial concerns.

Minor adjustments were made to wording on the items pertaining to dependency on the initial draft and, a second draft (sample B) was scrutinised by three counselling psychologists, all of whom had palliative care experience. All three counselling psychologists had similar concerns as the bereaved former caregivers regarding the two items relating to emotional and practical dependence on the patient. They suggested reliance was a preferable word to dependence as, for some, ‘dependence’ is emotionally loaded. They also suggested being more specific about the ways in which someone may be practically reliant on the patient, for example by

adding “with the activities of daily living.” They all suggested that, in relation to the suicidal ideation item, it was better to explicitly ask rather than use a longer, less direct question. Four items were removed following the first three clinician interviews. They pertained to feeling at peace, a negative outlook on life, an inability to adjust or cope with the situation, and acceptance of the patient’s impending death. The clinicians thought that these items would not deliver clinically useful information for screening those in the elevated risk categories, and suggested substituting other similar items that would capture the information required.

In the third draft (sample C) four items were substituted for the four removed from sample B. The substituted items related to being able to overcome difficult life events, life seeming meaningless or hopeless, and appreciating what’s important in life since the patient’s diagnosis. As the psychologists had all flagged previous or co-existing mental health diagnoses, as perhaps the most important risk factor for complicated or prolonged grief, an item was added “I have been diagnosed with anxiety, depression, or other mental health condition.”

This draft (sample C) was then reviewed by three more grief counsellors via one-on-one interviews. Further adjustment was suggested for the two dependency/attachment items, firstly in relation to specifying in what ways a caregiver may be practically reliant on the patient and secondly the item relating to turning to the patient in times of need. The second half of the sentence was removed, as the question was double-barrelled and asked two different questions. The counsellors also saw drug or alcohol use as a red flag item and suggested they should both be asked as a yes/no checklist item. Comments related to asking more specific questions about the ways someone might experience somatic or panic symptoms; however, it was decided not to include these as this would be a screening tool, used by nurses and chaplains, rather than a diagnostic tool used by psychologists or grief counsellors. The aim would be that palliative care staff have sufficient information to *refer* the caregiver to a health professional appropriately trained in assessment who would make intervention plans if appropriate. It was suggested the item order be rearranged so that the questionnaire would begin with warm-up items; the more emotionally loaded items in the middle, and more general items at the end.

Throughout the advisory group interviews, a variety of item responses were trialled. All agreed that five responses was an ideal number that would allow flexibility in responses as well as a neutral position. Three responses may not give enough choice, and seven responses may be too difficult for a caregiver to think through when stressed. The belief responses (true/untrue) were preferred by the caregivers as a ‘gentle way’ of asking questions, whereas the bereavement service providers thought frequency responses (never/always) may be more clinically useful. The bereaved former caregivers stated that the frequency responses were acceptable and made sense.

#### **Step four: Revision of Items by Academic Team**

Each item on the sample C draft was then scrutinised by two psychology academics with expertise in both bereavement and palliative care research to ensure theoretical relevance, clarity, and parsimony of wording. Wording on many of the items was simplified so that the items became more focused on the underlying construct. An additional open-ended question was added to the second page asking if there had been “...anything identified in the questionnaire that needs to be addressed now?” The items relating to the use of alcohol or drug use and previous mental health diagnoses were removed, given the psychologists and counsellors had indicated they would be better asked as yes/no items on a checklist. As the advisory group psychologists and counsellors had indicated rumination was commonly expressed in counselling practice, particularly in relation to unfairness, two items referring to rumination were added to replace the two removed, given there is an association between rumination centred on injustice, social relationships and complicated grief (Eisma et al., 2014). The two substituted items were: “I can’t stop thinking about .....’s impending death” and “I can’t help thinking about how unfair .....’s terminal illness is.”

The layout of the measure was also reviewed by the academic team. The 20 items were designed to fit on one A4 page, with a second page for the two open-ended responses. Five responses were possible for each item. The final responses following the advisory group discussions were frequency responses: never, rarely, sometimes, often, and always. The use of frequency of thoughts or feelings as providing more useful clinical information was supported by the academic team. Each item corresponded with a number 1 to 5 across the frequency responses. Finally,

instructions on how to complete the measure were placed at the top of the list: “For each item, please circle the number that best describes you, or how you are thinking or feeling at present. Wherever a line, like this ..... appears, please answer the statement as if the name of the person you are caring for is written on the line.”

The final draft of the measure was given an interim label of ‘*Grief and Bereavement Assessment*’ (GABA) for the pilot phase (Refer to Appendix F for grief and bereavement assessment). This version was again viewed by the two bereaved former caregivers who both commented positively. They both completed the form in less than five minutes and thought it was understandable and easy to complete.

#### **Step five: Pilot of Grief and Bereavement Assessment (GABA) in Palliative Care**

The management of the three palliative care services, that had expressed interest in participating in the trial of the bereavement model earlier in the study, were contacted to confirm that they were still willing to participate in piloting the new measure. One service was a government community based domiciliary service, one was a consultative service in a government teaching hospital, and one was a privately administered 23 bed in-patient unit, reflecting the three models of palliative care services in Western Australia.

**Participants.** A total of 19 caregivers participated in the pilot across the three services (14 women, five men, *M*<sub>age</sub> = 56.5 years, age range 30-86 years). Table 6.3 below shows demographic information.

Table 6.3

*Family Caregiver Demographic Information (N=19)*

<b>Characteristics</b>	<b>n (%)</b>
<b>Gender of caregivers</b>	
Women	14 (73.6)
Men	5 (26.3)
<b>Caregiver relationship to patient</b>	
Adult child	10 (52.6)
Spouse	4 (21)
Parent	3 (15.8)
Sibling	1 (5.3)
Grandchild	1 (5.3)
<b>Patient's diagnoses</b>	
Cancers	7 (36.8)
Intracranial bleeds	3 (15.8)
Lung diseases (not cancer)	2 (10.5)
Organ failure	2 (10.5)
Neurodegenerative conditions	2 (10.5)
Aged decline	1 (5.2)
Unsure of diagnosis	2 (10.5)
<b>Length of patients' diagnoses</b>	
>10 years	1 (5.2)
Between 3 and 10 years	3 (15.8)
Between 1 and 2 years	4 (21)
Between 2 and 6 months	4 (21)
Between 4 and 6 weeks	1 (5.2)
< 1 week	4 (21)
Unsure of length of patients' diagnoses	2 (10.5)
<b>Patient length of time under care of PC service</b>	
Between 1 and 3 years	3 (15.8)
Between 2 and 10 months	4 (21)
Between 6 and 8 weeks	1 (5.2)
< 1 week	9 (47.4)
Unsure of length of time under care of PC service	2 (10.5)
<b>Patient length of stay this admission</b>	
Between 2 and 6 weeks	3 (15.8)
< 1 week	12 (63.1)
Unsure of length of stay this admission	4 (21)

**Procedure.** Meetings were held with the management at each organisation to plan how the pilot would proceed within their service. The domiciliary service preferred that staff identify and approach the caregivers deemed appropriate for assessment. The staff then notified the researcher of caregiver contact details to make an appointment to complete the assessment at the caregiver's residence; post-assessment the completed forms were taken to the service's office so that staff could review the assessment and take action accordingly if this was deemed necessary. The consultative service suggested the researcher recruit caregivers at two out-patient symptom control meetings conducted weekly and to assess caregivers who were willing to participate. The in-patient unit indicated a preference that the researcher attend the weekly multi-disciplinary team meeting and assess caregivers identified by staff at the team meeting.

At the consultative service in the acute care teaching hospital, outpatient clinics were initially trialled to recruit caregivers; however, it was evident that the majority of patients were in good health and attended clinic unaccompanied by caregivers. It was possible that the caregivers who did attend would not be thinking of grief and how they might manage following the patient's death. Management was again approached to discuss alternative recruitment strategies. The clinical nurse manager facilitated recruitment of inpatients, initially asking caregivers to contact the researcher if they wished to proceed with the assessment. However, it became apparent that assessment using the measure was best completed during windows of time when the patient was receiving care, (such as hygiene or re-positioning), and the caregivers were waiting to return to the bedside. It was more expedient to have the participant information and consent forms, measures, and feedback forms on hand in the event a caregiver was available and willing to do the assessment. Following explanation and written consent the nurse left the measure and feedback forms, along with reply-paid, hospital-addressed envelopes, with caregiver participants. The nurse would return to collect them or, they would be posted back to the hospital. Six assessments however, were not returned to the hospital following separation from the service, and it is not known if these caregivers participated in the assessment process.

At the in-patient unit, the researcher attended the weekly multidisciplinary team meetings so that she could identify potential caregivers. Some of the patients were

admitted for respite care, and many patients were awaiting transfer to longer term care facilities, with some patients admitted for end-of-life care. The staff did not want the caregivers of patients in the terminal phase to be approached, fearing assessment would overwhelm them. Given the restrictions about approaching caregivers with patients in the final days/hours of life, finding caregivers by the bedside proved to be difficult. Management was approached again to see if staff could be more pro-active in asking caregivers to participate in the assessment as part of their practice; however, management believed that the staff would need to be actively engaged through extensive prior education so that they would be more comfortable with caregiver self-assessment.

At both the in-patient unit and the consultative service, some caregivers were keen to do the assessment when they were approached, others preferred to think it through and complete it at their convenience. Following verbal and written explanation of the procedure, with written consent from the caregivers, participants were then asked to complete the printed, two page grief measure (GABA) and feedback questionnaire to evaluate caregiver acceptability of the assessment process. (The feedback questionnaire evaluation will be discussed in Chapter Seven).

**Findings from Caregiver Responses to the Measure's Items.** The measure consisted of 20 items which were rated across five frequency possibilities; never (1), rarely (2), sometimes (3), often (4), and always (5). As the measure has not yet been validated it was not possible to use scores to match support with need or determine a cut-off score; however, the response each caregiver assigned to each item was checked by staff and by the researcher, so that any concerns raised by a caregiver could be responded to by the service's staff with appropriate support. A range of responses was given across each of the items by each of the family caregivers and is shown in Table 6.4 on page 107.



Table 6.4

*Family Caregiver Responses to Measure Items*

Item	Response categories						n (%)
	never	rarely	sometimes	often	always	no response	
Not ready for impending death	4 (21)	5 (26)	6 (31.5)	3 (16)	1 (5)	0	
Confused, unsure what's happening	7 (37)	7 (37)	5 (26)	0	0	0	
Avoids thinking about what's happening	4 (21)	6 (31.5)	4 (21)	4 (21)	1 (5)	0	
Support from spiritual beliefs	9 (47)	0	1 (5)	3 (16)	6 (16)	0	
Reliance on patient for support	10 (53)	3 (16)	1 (5)	2 (10)	0	3 (16)	
Reliance on patient emotionally	5 (26)	3 (16)	2 (10)	4 (21)	2 (21)	3 (16)	
Fearful of life after the patient's death	5 (26)	2 (10)	3 (16)	5 (26)	4 (21)	0	
This is the worst experience	2 (10)	2 (10)	3 (16)	7 (37)	5 (26)	0	
Intrusive thoughts about the impending death	0	3 (16)	6 (16)	5 (26)	5 (26)	0	
Appreciate the important things in life	0	1 (5)	1 (5)	8 (42)	9 (47)	0	
Worry	0	2 (10)	8 (42)	6 (32)	3 (16)	0	
Guilt about past choices made	7 (37)	8 (42)	4 (21)	0	0	0	
Thoughts of unfairness	4 (21)	5 (26)	2 (10)	3 (16)	5 (26)	0	
Feelings of anxiety and panic	4 (21)	4 (21)	7 (37)	3 (16)	1 (5)	0	
Feelings of meaninglessness	10 (53)	1 (5)	4 (21)	3 (16)	0	1 (5)	
Suicidal ideation	15 (79)	1 (5)	2 (10)	1 (5)	0	0	
Managing well	2 (10)	4 (21)	7 (37)	6 (32)	0	0	
Health is suffering	4 (21)	3 (16)	6 (32)	2 (10)	4 (21)	0	
Overcoming difficulties in life	0	3 (16)	4 (21)	7 (37)	5 (26)	0	
Good support (family/friends)	1 (5)	0	3 (16)	2 (10)	13 (68)	0	

Responses to the items from four of the caregivers had indicated some distress which enabled timely conversations with staff and support to be put in place if needed. Two were spouses whose partners had very recent admissions and referrals to palliative care, and two were parents caring for adult children with cancer. There were also two open-ended qualitative questions at the end of the measure. The first question asked if there was anything that might affect the caregiver's ability to care for themselves or others they had responsibility for during the coming weeks. Three caregivers responded they were very tired, and one answered that he/she was dealing with a lack of sleep and found the numerous medical appointments stressful. Three caregivers indicated they would have problems if they became ill themselves. Another caregiver indicated financial matters were of major concern. The second question asked if there was anything in the questionnaire they would like to have addressed immediately. Only one caregiver responded that he/she needed more palliative care support at home. Allowing the caregivers to make such statements if they so desired, facilitated conversations with staff and opened the way for earlier referral to social work, chaplaincy, or counselling support.

Just over half of the caregivers were adult children caring for a parent, or grandparent, who was dying, with almost a quarter caring for a partner or spouse; a further 15% were parents caring for an adult child. Close relationships, in particular parental or spousal relationships, are associated with poorer bereavement outcomes (Thomas et al., 2014). Sixty-three percent of the patients had been admitted to the palliative care service less than one week, with just over 20% of the terminal diagnoses being made under a week, indicating that for many there had been little time to prepare for end-of-life and the impending loss of their family member. Later referral to palliative care, when the patient's condition is very poor, has also been found to be associated with poor bereavement outcomes (Kelly et al., 1999).

### **Recruitment of Caregivers: Issues Encountered During the Pilot Phase**

When the trial was ready to commence in October 2014, the in-patient unit management requested that the participant information forms state more explicitly that the service's palliative care staff would be reviewing the completed measure as a part of their assessment process. This required administrative amendment applications to the three Research Ethics Committees resulting in a delay. When the pilot was ready to

commence at the community domiciliary service in February 2015, the service was notified of closure in the coming months; as such, the management preferred to discontinue the trial given the amount of work involved in closing the service. As a result, only two caregivers completed the GABA and feedback form at the community service. The pilot commenced at the in-patient unit towards the end of March 2015; however, as mentioned earlier, recruitment of participants was difficult to achieve by the researcher without staff facilitating the assessment process; as such, only three participants were recruited from the in-patient unit.

## **Discussion**

The aim of this third phase was to develop a caregiver self-report grief measure, with items centred on risk factors for prolonged or complicated grief, suitable for use in palliative care settings prior to the patient's death. The measure was aimed to be brief enough to be acceptable to caregivers as they cared for the patient in the approach to end-of-life, yet to deliver clinically useful information for palliative care health professionals in order to make decisions as to who needs follow-up after the patient's death.

**Risk factors or grief responses?** The process of developing a new grief measure began with gathering a list of risk factors and predictors for complicated grief. In searching the grief and bereavement literature for risk factors and predictors of complicated or prolonged grief, it was surprising that only one systematic review of risk factors (Lobb et al., 2010) was located. Through accessing cited references, additional articles were located that enlarged upon various risk factors. The categorisation of risk factors that would be most relevant to the pre-death period in the palliative care setting proved to be challenging. Many categories overlapped, such as rumination and traits, or dependency as a trait and attachment. While attachment is considered to play a major role in one's adjustment to grief (Wayment & Vierthaler, 2002), it is also very difficult to assess attachment effectively, as was apparent with the confusion with attachment items by advisory group members. It was noted when collating the scores on the GABA three caregivers omitted responding to these two items, indicating that there may still be confusion about their meaning and how to respond to them. As mentioned above, dependency is a complex and multifaceted concept that relates to an individual's interactions with others and, as such, may give

insights into attachment, given cognitions relating to self-efficacy, needing approval from the other, anxiety and worry resulting from absence of the other, and seeking proximity to the other are facets of dependency (Morgan & Clark, 2010). However, as Morgan and Clark (2010) suggest dependency as a construct is poorly defined and, as such, is very difficult to assess, particularly when presented as a risk factor item. The brief risk factor items therefore required a great deal of thought and discussion about wording and whether or not they would capture the required information, particularly when assessment will be undertaken by health professionals without psychological training in assessment.

**Brevity or clinically useful information?** Being mindful that the measure is intended to screen caregivers to identify those at potential risk of prolonged or complicated grief, by a variety of health professionals without psychological training, was a tension throughout the development of the measure. Assessment of grief, using established measures and expertise, is more appropriately conducted by health professionals adequately trained to assess and plan interventions, and the aim for palliative care services is to direct those caregivers at risk to services for such follow-up. A related additional tension was between a need for the measure to be brief so that it would be user-friendly for caregivers, whilst also providing useful clinical information. Until the measure is validated psychometrically, it will be difficult to gauge whether such a brief measure is sufficiently robust to be clinically useful in identifying those who need referral for follow-up assessment or support.

**Checklist or self-report items?** As advised by the bereavement service providers, important risk factors linked with complicated or prolonged grief, such as previous or comorbid mental health conditions, drug or alcohol use (Jordan & Litz, 2014), and financial stressors (Thomas et al., 2014) are best approached as yes/no questions on a checklist. These types of questions at any point in time require a dichotomous (yes/no) response, rather than a frequency or agreement response on a five point scale. A checklist could be completed quickly, rather than taking time to consider a variety of responses. The addition of such questions to the self-report would extend it and may prove too taxing for a caregiver to complete. Such a yes/no checklist was not considered as a part of this study, but is deserving of future consideration if comprehensive information in relation to assessing risk is to be gathered.

Peri-death situational factors, such as difficult or traumatic deaths and patient care issues, are also known risk factors (Thomas et al., 2014). These factors would be difficult items for a caregiver to rate across a Likert type scale; rather, these are checklist items more appropriate to palliative care staff assessment. Information on other factors such as gender is important, as women are considered at higher risk than men, and also certain relationships such as parental or spousal relationships are more likely to be linked with complicated grief (Thomas et al., 2014). Such information would be more appropriately captured by the multidisciplinary team. Family functioning throughout the illness can also influence bereavement outcomes (M. Stroebe & Boerner, 2015; Waldrop, 2007), but was not incorporated in the development of this measure as it was difficult to determine if caregivers would be able to rate their own family function with a single item on a measure, given the measure was required to be brief. Such family function items may also cause confusion for those caregivers without family.

### **Strengths of this Phase of the Study**

The use of one-on-one, low-structured interviews that were conducted iteratively across drafts of the measure facilitated in-depth focus on each of the items and allowed each item to be thoroughly explored from a variety of perspectives (Hesse-Biber & Leavy, 2011). Such attention to each item in detail provided clarity in relation to whether or not an item should be altered, or removed and substituted for another item. The study was also strengthened by the collaboration with the advisory panel of bereavement service providers, bereaved former caregivers, and the academic team experienced in bereavement and palliative care, who worked systematically through various drafts of the measure. The diversity of roles, from counselling psychologists, counsellors and social workers across a variety of clinical practice settings contributed a breadth of perspectives when creating assessment items in relation to applicable interventions for complicated grief. The bereaved former caregivers' contributions, given they had both had extensive experience caring for loved ones in the palliative care system, were invaluable in gaining the consumer's perspective, thus ensuring the measure would be understandable and acceptable for use in the clinical setting. The final review by the academic team also ensured the measure was reflective of the underlying constructs and grief dimensions. As such, it is expected that the items on the final draft that was piloted have contributed to the

measure having acceptable content validity (that is, the items are representative of predictors of complicated or prolonged grief) and face validity (that is, the items appear to be sound constructs) (Jackson, 2003).

### **Limitations of this Phase of the Study**

The small sample size of the caregiver participants who piloted the measure is a major limitation to this study. Additionally, the lack of participation and obstacles to recruitment of participants at the domiciliary and in-patient services mean that a comparison between the service types could not be made. It is possible that late referrals to palliative care, which seem more likely to occur in a consultative situation in an acute hospital than in a domiciliary service, may affect a caregiver's ability to think about end-of-life and grief responses. Almost half of the caregiver participants in this study were caring for a patient who had been designated palliative care for less than a week, with 63% reporting length of stay with the current admission as less than a week. As patients are spread across acute wards and departments in the acute teaching hospital, it is also more likely that caregivers may not be as aware of the patient's palliative care status, as they would be at either an in-patient or domiciliary service. As such, caregivers may not engage with the measure with the mindset of someone who is about to be bereaved.

The problem with recruiting caregivers was also instructive of how caregiver assessment might be administered in practice. It seems that the most appropriate time to have conversations with caregivers, and ask them to engage in assessment, is when the patient is receiving care and the caregiver is temporarily away from the bed. Because the consultative service staff do not provide direct patient care in a palliative care unit, rather they visit various wards and departments on an as needs basis, they were not there 24 hours per day to speak with family members. Logically it would seem more likely that assessment would be more easily coordinated at in-patient and domiciliary units, where caregivers are aware that their patients are designated palliative care. Additionally, at an in-patient unit staff members provide patient care across 24 hours per day and, as such, there would be many instances when a caregiver might have a few minutes to undergo the assessment process while the patient sleeps or receives care. Such logistical and systems of care issues were highlighted by the reference group in the previous phase of the study, and were discussed in Chapter Five.

Alongside a small sample size, a further limitation of piloting the measure relates to the characteristics of the caregiver participants. Almost 75% were women, with just over 50% of all participants being adult children caring for a terminally ill parent. All participants, bar two (a man and a woman who identified as Indian ethnicity) were White Australians from European backgrounds, and ninety-five percent stated English was the main language spoken in the home. With such a sample it is not possible to elucidate how cultural, ethnic or religious factors might influence the assessment of grief responses.

On a positive note, when the caregivers were given the opportunity to openly express their concerns, and in particular take advantage of noting matters they would like addressed, the team members were able to respond to the issues in a timely fashion. Without the opportunity for the caregivers to express these needs or concerns directly, it would possibly take much longer for issues, (such as financial matters or difficult emotions), to become apparent and be responded to. Recent research has shown benefits to caregivers when their concerns have been expressed and responded to appropriately (Aoun, Grande, et al., 2015; Ewing et al., 2013). The measure therefore shows promise in giving caregivers a much needed voice at a difficult time.

### **Future Directions**

Whilst reliability of the GABA as a measure of grief responses was not within the scope of the present study, the measure may have a variety of applications in the clinical setting; however, acceptability of the measure by caregivers and health professionals in the palliative care services needs to be gauged first. Should the measure be deemed to be acceptable for use and have utility in clinical settings, the logical next step would be to subject the measure to psychometric validation studies. However, there needs to be further dialogue with palliative care health professionals and bereavement service health professionals in relation to this self-report situated within a structured variety of assessments that would also encompass a brief caregiver yes/no checklist as mentioned above, that would capture a greater variety of important risk factors. As mentioned earlier, some of the risk factors are more easily gauged by the multidisciplinary team. In short, a robust pre-death assessment would likely encompass a brief caregiver self-report measure, as well as a brief caregiver yes or no checklist enquiring about previous or comorbid mental health conditions, financial

considerations, support, previous losses, responsibility for others and coping responses. In addition to these caregiver assessments, the multi-disciplinary team is well placed to gather comprehensive information such as next-of-kin and family interactions, situational features relating to patient care and the death, and demographic information. Such a three pronged assessment may more comprehensively capture a diversity of information from a variety of perspectives.

## **Conclusion**

The aim of this third phase of the study was to develop a brief caregiver self-report grief measure, with items centred on risk factors for prolonged or complicated grief, suitable for use in palliative care settings prior to the patient's death. The measure was developed across five stages, starting with a list of risk factors and predictors of prolonged or complicated grief, rather than grief symptoms, on which to base the items. Drawing upon the experience and expertise of an advisory group of bereavement service providers and bereaved former caregivers, as well as an academic team of palliative care and bereavement researchers, ensured the items on the measure had greater clinical application and utility, and were grounded in the literature, prior to the pilot in three palliative care services.

Logistical issues emerged during the pilot phase relating to the most appropriate time to assess, how to assess the caregivers, and how to navigate systems of care issues, where services have differing patient contact and length of patient stay. The next step is to assess how caregivers found the assessment process and to evaluate whether or not the measure might have utility in clinical practice through discussions with the health professionals from the participating palliative care services. These evaluations will be the subject of Chapter Seven.



## **CHAPTER SEVEN**

### **Evaluation of the Bereavement Risk Assessment Model**

“A theme may seem to have been put aside, but it keeps returning – the same thing modulated, somewhat changed in form.” - Muriel Rukeyser

#### **Chapter Overview**

This chapter gives an account of the outcome from the pilot of the brief grief measure which was developed in phase three of the overall study (described in Chapter Six). Chapter Seven commences with the evaluation of data gathered from the feedback questionnaires completed by caregivers following their completion of the grief and bereavement assessment (GABA) questionnaire. Evaluation of use of the measure in relation to clinical practice was also conducted through focus group and one-on-one interviews with palliative care health professionals and management at the participating services, and is discussed at length in this chapter.

#### **Introduction**

Evaluation is central to the process of action research, rather than an addition to the research. As such, researchers need to build evaluation in to the research design at the outset and this should be reviewed and adjusted if necessary throughout the study (Hart & Bond, 1995). Evaluation informs the outcome of the study, and also informs the research process and the direction that the study may take by providing insight into, or facilitating decisions that are to be made about the intervention (Frogatt & Hockley, 2011). As noted by Khanlou and Peter (2005) the research participants themselves evaluate the research and its outcomes.

As discussed in Chapter Three, the current bereavement risk assessment model was modified from an original plan of using existing grief measures at three points in the caregiving and bereavement trajectory (Sealey, O'Connor, Aoun, et al., 2015) to using the newly developed measure (GABA) prior to the patient's death in response to the reference group recommendations. The aims of the evaluation remained the same as originally intended; however, the focus switched to evaluating the new risk assessment model which consisted of the newly developed measure (GABA) applied

in the period before the patient's death. The GABA measure was piloted on caregivers (n=19) at three palliative care services and has been described in Chapter Six.

The aims of the evaluation phase of the study were as follows:

- To evaluate caregivers' acceptance of completing the grief measure.
- To evaluate palliative care health professionals' acceptance of the bereavement risk assessment model in terms of feasibility for use in clinical practice.
- To evaluate acceptance of the bereavement risk assessment model by palliative care service management in relation to its longer term sustainability in practice and application to policy.

## **Methods**

### **Participants**

The 19 caregivers who had participated in the pilot at the three palliative care services (14 women, five men, *M*age = 56.5 years, age range 30-86 years) all participated in the evaluation of the new measure. Table 6.3 in previous chapter shows demographic information (see page 104).

### **Materials and Procedure**

*Feedback questionnaire.* Following completion of the grief measure (GABA) as discussed in Chapter Six, caregivers were asked to complete a brief feedback form, adapted from one used in a population based survey of bereavement risk and support needs (Aoun, Breen, et al., 2015). The form gathered information about caregivers' experience of using the measure. (Refer to Appendix for G feedback form).

The feedback form comprised two parts. Section A of the feedback form enquired about ease of completion of the measure. The participant selected one of five options: very easy; easy; neither easy nor difficult; difficult; and very difficult. The questions following related to whether or not the GABA measures questions were clear and appropriate, and if they adequately assessed their caregiver needs. A yes or no check-box was used. Space was provided to expand on items indicating if any were difficult to answer, unclear, or inappropriate, and why. Item six invited caregivers to

indicate if any other questions should have been included. The feedback form also asked participants how long it took to complete the GABA measure, and how important they believed it was for the palliative care service to be concerned about them as caregivers. Three options were given: very important; somewhat important; or not important at all. There was also space to add any other general comments.

Section B of the feedback form gathered demographic information in relation to sex; age; relationship to the patient; patient's diagnosis and length of diagnosis; palliative care service contact and length of stay this admission; whether or not the caregiver had responsibility for the care of others; main language spoken at home; cultural background; and educational level. (Information on patients' diagnoses and palliative care contact is reported in Table 6.2 in chapter six). Caregiver characteristics are reported in Table 7.1 below.

*Table 7.1*

*Caregiver characteristics*

<b>Caregiver characteristics</b>	<b>n (%)</b>	
<b>Sex</b>	<b>1.</b>	
Women	2.	14 (73.6)
Men	3.	5 (26.3)
<b>Age (years)</b>	<b>4.</b>	
Women (30 – 77 years, Mage 52.9)	5.	
Men (45-86 years, Mage 66.6)	6.	
<b>Main language spoken at home</b>	<b>7.</b>	
English	8.	18 (95)
Not English	9.	1 (5.3)
<b>Education</b>	<b>10.</b>	
No formal education	11.	1 (5.3)
Primary school	12.	0
High school	13.	7 (36.8)
Diploma/trade/certificate	14.	4 (21)
University	15.	7 (36.8)

## Results

**Findings from the caregiver feedback form.** The length of time taken to complete the GABA measure ranged between five and 30 minutes ( $M_{\text{time}} = 10$  minutes). These data are presented in Table 7.2 below along with caregiver scores on ease of completion of the measure.

Table 7.2

*Time taken and reported ease of completion of measure*

<b>Completion of measure</b>	<b>n (%)</b>
<b>Time taken to complete measure</b>	
5 minutes	7 (36.8)
7 minutes	1 (5.2)
8 minutes	1 (5.2)
10 minutes	5 (26.3)
15 minutes	4 (21)
30 minutes	1 (5.2)
<b>Ease of completing measure</b>	
Very easy	5 (25.3)
Easy	7 (36.8)
Neither easy nor difficult	5 (26.3)
Difficult	2 (10.5)
Very difficult	0

The two caregivers who reported that the measure was difficult to complete were both men caring for an adult child; one was a caregiver, aged in his late 80s, who indicated English was the main language spoken at home and the other stipulated that English was not the main language spoken at home. When asked to comment on what was found to be difficult, the older caregiver commented “I don’t know what you’re trying to get at. “ The other caregiver did not comment. Despite these reported difficulties with the measure, all caregivers rated the measure as being clear. One caregiver indicated that English was not the main language spoken at home, and one caregiver indicated that he had no formal education.

All but one caregiver indicated that the items were appropriate. One caregiver, who was caring for her grandmother, commented on the use of the word ‘terminal’ in item 13. She said that her grandmother was experiencing ‘general aged decline’ rather

than a terminal illness. It was noted that her grandmother had been in the hospital for two days and, as such, there may have been insufficient time for the granddaughter to comprehend the transition from acute restorative care to palliative supportive care.

When asked if the items on the measure met their needs, two caregivers suggested additions. One caregiver commented that financial and insurance concerns could be added, and another suggested adding “what happens next, funeral, and afterlife.” Fifteen (79%) of caregivers believed it was very important for the palliative care service to be concerned about caregiver needs, with four (21%) stating it was somewhat important. None rated it as being of no importance at all. When asked to offer any comments in general, three caregivers commented how happy they were with the palliative care service, with one caregiver writing: “I’m moved that my needs are thought of.”

In summary, the 19 caregivers who had completed the grief assessment questionnaire also completed the feedback form. The majority found the measure reasonably easy to understand and most were able to complete it within 10 minutes. However, the assessment protocol will also need to be acceptable to palliative care staff and have utility in clinical practice. Therefore evaluation was also conducted with the participating services.

### **Evaluation of Health Professionals and Management at Participating Services**

As discussed in Chapter Six, three local palliative care services agreed to participate in the pilot of the new grief measure. Shortly after commencing recruitment the domiciliary service ceased operating and, as a result, only two caregiver participants were recruited at that site. Evaluation of the model was not conducted with that service. Evaluation at the in-patient unit was conducted via a single focus group with multidisciplinary team members using a semi-structured interview. Evaluation was conducted at the consultative service in the teaching hospital via a semi-structured one-on-one interview with the Clinical Nurse Consultant/Nurse Manager of the palliative care service.

## Methods

**In-patient unit evaluation: study design.** Focus group methodology was deemed the optimal method to evaluate the health professionals' views at the in-patient unit. Focus groups are often used to collect data in evaluation research because they allow the researcher to understand inductively in an in-depth way a number of issues and ideas relating to the topic of evaluation. Such data provide a rich source of information that the researcher may not have been able to access by other means (Hesse-Biber & Leavy, 2011). Such evaluation may focus on the strengths or weaknesses of an intervention, or whether or not a program was deemed successful; as such, the information gathered may guide the development of a new intervention or program. Focus group research is therefore anticipatory; whereby the researcher is looking towards what is needed to deal with the future (Macnaghten & Myers, 2004).

An additional advantage of a focus group method is that a number of participants gathered together facilitate a dynamic interaction between group members, highlighting not only a range of similar viewpoints, but also different perspectives of the various group members and illustrates the frameworks by which the participants understand their setting or workplace. This contributes to a shared understanding for the focus group members and is useful in applied research where the aim is to change practice or implement new practice. The conversation resulting from interaction between group members provides additional data from that which may be collected from individuals alone (Hesse-Biber & Leavy, 2011).

**Consultative service evaluation: study design.** A one-on-one semi-structured interview was conducted so as to maintain focus on evaluation of the bereavement risk assessment model, and also allow the respondent latitude to add information and develop the conversation in relation to issues that the researcher may not have been aware of (Hesse-Biber & Leavy, 2011). (Refer to appendix H for semi-structured interview agenda.)

**In-patient unit evaluation participants.** Four health professionals, three women and one man, volunteered to participate in the focus group. Their ages ranged between 38 and 54 (*Mean* 44.5 years). The members represented role designations typical of a palliative care multidisciplinary team: one was a clinical nurse manager; one was a clinical nurse; one was a palliative care physician; and one was a chaplain.

Their years of palliative care experience ranged from 11 years to 25 years and together their years of palliative care service totalled 68 years (*My*years of experience 17 years).

**Consultative Service Evaluation: Participant.** The clinical nurse consultant at the palliative care consultancy unit of the large teaching hospital agreed to participate in the interview evaluation. She had worked in that role for five years, and had 12 years of palliative care experience.

**In-patient unit procedure.** Following the pilot of the new measure as a bereavement risk assessment protocol, the manager of the in-patient unit was approached to confirm that the unit was still willing to participate in the focus group evaluation. An invitation to participate in the focus group was extended to staff via a notice in the staff office, and a date for the meeting was set to follow a weekly multidisciplinary team meeting. The focus group was conducted in the palliative care unit's seminar room used for weekly team meetings. Purposive sampling was utilised so that a cross-section of multidisciplinary team members would be represented in the group in order to obtain a range of perspectives.

Because there had been issues with recruitment at the in-patient site, a research assistant, not connected with the study, was employed to facilitate the focus group meeting. The facilitator was a clinical nurse consultant with over 30 years of nursing experience who also has eight years of research experience. It was anticipated that a facilitator with extensive hospital service would be likely to build rapport with participants and enable them to engage in the discussion if they felt the interviewer was trustworthy and familiar with their situation (Hesse-Biber & Leavy, 2011). The interviewer was briefed on background to the research and the issues encountered with recruitment at the in-patient site. A short semi-structured interview agenda was set to guide the discussion so as to give participants an opportunity to contribute information on important issues (Hesse-Biber & Leavy, 2011). (Refer to appendix I semi-structured interview agenda). The meeting discussion was digitally recorded and transcribed verbatim following the meeting.

**Consultative service procedure.** Following a telephone conversation, an invitation to participate in the evaluation interview was sent by email, and a mutually agreeable time was set up. The meeting was conducted in the palliative care unit's meeting room.

**Analysis of data: in-patient unit and consultative service.** Inductive thematic analysis was applied to the transcribed data as per Braun and Clarke's (2006) approach. This entailed listening to the recordings several times to become familiar with the content. The recording was transcribed verbatim following each meeting. Preliminary themes in relation to the evaluation of the model were identified from larger groupings of ideas and concepts.

## **Results**

Findings from the evaluation at each of the two services were markedly different and will be presented separately; the in-patient unit themes will be outlined first followed by the consultative service findings.

**Findings From In-Patient Unit Focus Group.** Following thematic analysis of the data (Braun & Clarke, 2006), three themes were identified: issues relating to the study protocol and miscommunication; expectations in relation to a feasible bereavement risk assessment model; and barriers to bereavement risk assessment in the in-patient service.

***Problems with the study protocol and communication.*** The Clinical Nurse Manager believed that the pilot of the new measure with caregivers was too brief stating, "I actually don't think that the study went on for long enough for us to actually get any reasonable feedback about it."

At management level there was confusion about the research protocol in terms of recruitment and administering the assessment that had filtered through to the staff:

But our understanding was that she [the researcher], she was doing the validation and we'd checked with her a few times that she was going to do the recruitment. When we've had other people doing studies here there has, there has been an expectation that the researchers will come; they will identify the patients, but they've expected the nurses to do the recruitments. (Clinical Nurse Manager)

The Clinical Nurse stated:

I think possibly we misunderstood how much, you know, identifying the, the people we, I think there was a misunderstanding that that was part of what you



know we were going to do. I think we thought [the researcher] would approach us with team meetings.

The Chaplain added: “I just assumed that it [the assessments] was happening as she [the researcher] came along to the meetings and was processing who was there.” The Clinical Nurse Manager did say that the researcher had reported to management that “she’d tried to feedback to a couple of the nurses about things that she’d picked up [in the assessments]” but the Manager had not elaborated on that point.

Indeed, recruitment of potentially eligible caregivers had been difficult as many caregivers were not at the bedside when the researcher visited the unit. As the Clinical Nurse Manager said:

[The researcher] had frustration in trying to track down carers and just because of the short time frame it hasn’t happened... Maybe they’re [recruitment issues] partially our fault as well, we have tried to identify patients at the, or carers at the meeting, who, who could possibly be recruited for it but it’s been, it’s been difficult.

The Clinical Nurse Manager went on to say later in the interview “It’s notoriously difficult doing research in palliative care, and then again doing research in bereavement.”

It was evident that there had also been a lack of understanding about the study’s aims which was to develop a bereavement risk assessment model, rather than primarily to validate a measure. In terms of the overall study the Clinical Nurse Manager said:

I think possibly we misunderstood that this, that this was a tool that she [the researcher] was developing and getting some validation for... and was something we could actually incorporate as part of our practice. I saw this tool being incorporated into practice down here at about step 6 or 7. Not at step 1 and 2 [which] is probably developing it at getting the ethics and research approval and then the validation... We really haven’t had enough time to, to complete that loop of validation.

One contributing factor to this misunderstanding, according to the Clinical Nurse Manager, had been the Human Research Ethics Committee (HREC) documentation and the delay that the HREC approval process had created:

There was a delay in getting some, you know, the approval from the hospital to carry out the project. Because it was the proposal [documentation from the other health services' HRECs] that was put, was very wordy, and there was a lot of stuff for, for the CEO and the people, the ethics people, to wade through. Yeah, yeah and even looking at this you know I've got one, two, three pages to read, it's, there are stumbling blocks to yeah and we did have to ask [the researcher] for a shortened version.

Due to recruitment issues and having had only three caregiver participants, it had been difficult to assess the feasibility of the assessment model. The Physician noted: "The numbers have been very small, so, and I think it's been hard for us to get a feel of what, how the tool is working as well I think."

***Expectations in relation to the feasibility of use of the new measure as a bereavement risk assessment model.*** The Chaplain stated:

My initial response to this [GABA measure] is I'm saying 'great it's a tool we can use' and I look forward to it because I have actually seen the bereavement assessment at most hospitals, bereavement assessments they are ridiculous to ask people to do that.

Later in the interview the Chaplain added:

I want to see this all work. I really do want to see it work, because if we can have something that's been proven to achieve a certain outcome, and knowing the limitations and the possibilities of that opportunity, I wouldn't have a problem putting something like this as a part of our recommending it to be part of our file that, that we use to process stuff, and then used as part of the information we then use to assess the risk. They'll [assessment measures] work in certain contexts, other places they may not work, but you can still use that [GABA measure] to work through with...and if it became you know, it could be something we could use at the chaplaincy, or at counselling or nursing staff, or all across the board or something like that.

However, the palliative care Physician seemed reticent to add a self-report measure to present risk assessment practice, saying:

From the bits of feedback that she [researcher] got from other places, you could see that it may have been helpful. But I, I, it's [consultative service] a very different setting to what they were using it to here,... you would need to have more numbers on the ground for us to be able to reflect back clinical practice, is that what we are identifying as well in the patients families as being an issue to seeing what's on here [the GABA measure]. Because that's sort of, I guess, what we use as gold standard at the moment is really knowing the patients families and knowing and talking to them, and us being involved with them as a team. And us collaborating together and identifying well these, we are all finding the same thing, we are finding there is an issue.

***Barriers to bereavement risk assessment at the in-patient service and what would be required to implement a risk assessment protocol.*** It was considered ongoing education would be needed before a bereavement risk assessment protocol could become part of routine practice. The Clinical Nurse Manager said: "...there would have to be a really good education program and processes and incorporation into practice." The Chaplain stated: "I think the education about the explanation for us is, the people using the tool, to say this is what it's trying to identify. There was a presentation [by the researcher], so this is what we are trying to do." The Clinical Nurse Manager responded: "More information than education, it was information about the, about the project. It wasn't education and we are going to do this..." The Chaplain further noted "...these sort of things you need to educate several times."

Concern was raised by the Chaplain that a self-report measure may add to staff workloads: "...in this environment we have our set tasks to do and while we want to support this [assessment] it's um yeah... I've got to process this information amongst all the other stuff that has to be done by everyone."

However, apprehension about providing a response to any concerns that may have been raised by caregivers completing the GABA measure became apparent. The Clinical Nurse Manager said:

Yeah but we have to work through it. You know, actions to follow. You know as in question 16 [an item on the GABA measure] ‘I had thoughts of ending my own life’. Well don’t ask the question unless you’ve, unless, unless you’ve actually got...[The Chaplain interjected] a procedure in place or something in place.”

So I think if this [GABA measure] had been given to some of the nurses to go and do with the carer for instance that, that could have been quite hard you know as has been said if, if that question they had said ‘yes’. You know, and you’ve got maybe someone who is not that experienced, what happens then you know? So you really are opening up a can of worms sometimes and not, not always being equipped to deal with what comes out. (Clinical Nurse)

Number 9 [an item on GABA measure] ‘I can’t stop thinking about you know (Peter’s) impending death’; well that’s for a busy nurse and, and you’ve gone and you’ve gone through the questionnaire with them. You are going to, you are going to need an hour and a half or two hours to sort that out. (Clinical Nurse Manager)

In conclusion, the Clinical Nurse Manager summarised the potential for the utility of the measure at the in-patient unit:

So it’s a matter of, if we did take it up, we’d have to really think about how we were going to implement it. Who was, who was going to set it out? What the places would be, how we would educate people, and who would we refer them on to. It’s not a 5 minute change to practice. (Clinical Nurse Manager)

**Findings From Consultative Service One-on-One Interview.** Three themes were identified in relation to the use of a bereavement risk assessment protocol at the consultative service: the assessment as a process relating to barriers such as logistics of contact with caregivers; the benefits of the assessment and its potential utility in future practice; and requirements to overcome barriers for applicability in clinical practice. All comments were made by the Clinical Nurse Manager who was interviewed.

*The assessment as a process: logistical problems and barriers.* “A majority of people were able to answer the questions...the only thing that made it more time consuming was the evaluation” which was a part of the research process, rather than the risk assessment. She added: “I don’t think ticking boxes is an issue” [that might deter caregivers from accepting a self-report assessment].

However, contact with caregivers was a logistical problem due to the nature of the consultancy service where nursing care is not delivered by palliative care staff:

It’s the fact that I’m transient, I come and go. I don’t always catch the families...because they don’t always come in at the same time. Sometimes those friends or family that are there are not the ones that would be completing the forms, and then when they do fill them in, they don’t want to fill them in at that point in time. It’s quite a stressful time [for family caregivers] and they may be needing to go off somewhere or something. Because we are still a busier, more acute environment, so that is more difficult to capture that group.

Reply-paid stamped-addressed envelopes had been left with the caregivers to return once completed; however, only two or three were returned. “If you actually were asking families that were in a hospice environment, you very definitely would not have the issues that I’ve had being a consultative service, because you are there all the time.”

A major barrier encountered by the consultancy service affecting the assessment process was that many patients and caregivers had undergone a sudden transition from acute curative care to palliative care at end-of-life and, as such, were not considered suitable to engage in the assessment: “Some people haven’t been appropriate to give the form. So we haven’t been able to turn around and say ‘Right! I could blanketly give every patient that is involved with palliative care this form, in this environment.’”

The majority of caregivers were not thinking ahead to the patient’s death and bereavement. Rather, they were struggling with the acuity of the patient’s care in an acute setting:

Most of them, once they got over what the tool was actually about, as in the patient is still there and they are talking about their bereavement. Some people do, or don't, cope with that so well, because they've actually not got to the point where they are thinking the patient's actually going to die and 'what am I going to do after?' - they are still battling with the beforehand. With some of our patients, because we are an acute hospital, they've moved very quickly, sometimes from acute injury insult, whatever that is, to bereavement in a very quick process, and sometimes it takes them time to catch up with that and they don't cope very well with that change. It's an enormous change and it doesn't seem to matter how old the people or the family are, or how old the patient is. Ultimately, people always want more time and if it's been taken away from them, there is not an expectation that that's [patient's death] going to happen.

Indeed, shorter lengths of patient stay with the transition from acute care to palliative care can be traumatic for many family members:

Within two days they [patients] are in a terminal phase. So it can be for some too traumatic. We've had to be more selective because we don't want to add to the trauma. Some people cope with it very well; others just don't cope with the situation around the patient moving into a dying phase. Getting them [caregivers] sometimes to think about that [patient's death and bereavement] and write that down is just too much, because they're just coping with the stress of what that process has been.

There was reticence to add to caregiver burden by asking them to take time to complete an assessment:

I'm always very aware that by filling in this form we seem to be taking away the family's time from the patient, and that, that is quite a difficult concern when I'm asking them to spend this time doing it [completing the measure] when that patient could very well be in their terminal phase... Although they [caregivers] sometimes need to be picked up after, I wouldn't want that [undergoing the assessment] to be viewed as a barrier to them spending time with their family. Even though it doesn't take very long it, it can be additional stress.

The staff member did not believe caregiver unpreparedness for the death would be an issue in a hospice setting where caregivers were “more used to the idea that the person is going to be dying and thinking about moving forward, that they would then be more able, and in the right frame of mind to answer it.”

While the rapid transition from acute care to end-of-life posed problems for the assessment of bereavement because of a lack of caregiver readiness, dying, death and bereavement were also culturally sensitive issues and affected a caregiver’s ability to respond to items on a questionnaire

Because we do have quite a high, not only indigenous but other nationalities...it may be then that it’s more appropriate from that perspective because culturally different groups would have issue with talking about somebody after they’ve died when they’ve not died. So I think culturally it would be more difficult for some to overcome those barriers.

As such, the wording on the GABA measure would require revision in some cases for use in this setting:

I think the, the types of wording; the catching the right people, what cultural background or what language those types of issues. Because I think we can try hard to try and overcome them but culturally they may never get to that point where they will accept this type of, of conversation. It’s the same as advanced care planning; some people just never get there. I think the point is that we catch those that are able, and we are at least are able to communicate with those, so they are the people that we might be missing.

Even in cases where cultural beliefs weren’t implicated, many people were uncomfortable with wording about dying and bereavement, preferring the hospital to remain focused on a positive outcome:

[Caregivers are] not wanting to fill it in [GABA measure], not wanting to think about it [impending death]; wanting to be very positive, still expecting treatments even if they are only fluids. They still see that as a life prolonging intervention. And, and really the medical system and the hospital to them it’s paramount it’s doing everything it can.

Additionally, the measure's wording was also a problem for those for whom English is a second language. Given the consultative service often used interpreters, this added a further layer of complexity:

Whether then it would be appropriate then to look at from an interpreter's perspective; how they feel, and they would be able to explain really what they are asking. Or whether it wouldn't be appropriate at all, and then we would need then to use the professionals to ask the questions and prompt those types of answers.

***Benefits of the assessment: Present advantages identified during the pilot.***

Using the measure in its present self-report form for those who were suitable to undertake the assessment facilitated a conversation between staff and caregivers: "It also gives us a conversation point - that ability for us to get to know the family that bit more. And that can't be a bad thing in our environment."

The staff member added that using the measure also enhanced the service's ability to provide a holistic service:

I think we do well a majority of times in getting the patients and the family to the point where you have a disease that you are not going to recover from. 'This is going to be your terminal phase and, and you know this is very sad and we can support you' and then that's as far as it goes.

In the instances when the GABA was used during the pilot, the staff member believed that it was useful in identifying those at risk: "I think people [staff and some caregivers] have still found it [GABA] useful. I think we still identified those that we felt at risk and it's good to have a tool to be able to do that."

This was particularly of value in the instances where staff found it difficult to decide on how to follow-up caregivers:

I think that still filling the form in has use to us when we actually come to do the bereavement [multidisciplinary team meeting and assessment of who needs follow-up]. It may dictate to us maybe people that require a 'phone call rather than just a card. It may highlight those borderline people. And maybe that's more



is the group we are looking at. Do we actually miss those that are a bit tenuous when it comes to the bereavement you know? They may be a bit up and down as to how well they're coping and they actually may need more support than we would initially see sometimes. I would see this as a form that would be able for us to identify these issues with the family, be aware of them, and use them in our bereavement planning. So attach it to our bereavement form that we that we fill-in to identify, you know, who does the bereavement and what the conversations have been.

***Benefits of the assessment: potential for the measure to have utility in the consultative setting in future.*** In the many cases where caregivers were not yet ready to think about bereavement due to the rapid transition from acute care to palliative care, where cultural sensitivity was required, or when English was not readily understood, the Clinical Nurse Consultant suggested that the GABA measure could be modified and incorporated into a staff conversation:

I think that what the difference is, is the people that are actually supplying the request or giving them the form, and the way that they explain it and discuss it with the family is what overcomes those barriers. ...we [clinicians] still could use, is even though we are not giving them [caregivers] a form, we could still use some of the concepts from the form and, then they would guide some of our questioning as to how the family were coping...for some people [caregivers]. So maybe some like, pertinent questions, maybe not an exhausting list like that list is [GABA], but a shortened version maybe with some, like a prompt sheet. They [the items on the measure] would guide some of our questioning as to how the family were coping.

In cases where reference to palliative care is problematic, the GABA may facilitate conversations that help caregivers more readily understand the benefits of palliative care involvement:

When you go to palliative care, they have this preconceived idea about what it is about, what the death's going to be. And you know 99% of people think they should have loads of pain and it's going to be a terrible process. It's a matter of talking through that, overcoming it, getting people to understand really who we

are, and the good that can be provided by our involvement. And this [GABA assessment] is very much part of that process.

The assessment measure would be of value as a part of the advanced care planning process:

I think as we move towards being more involved and talking more about advanced care planning and the role of advanced health directives and that, I think this could very well be, be a part of that thinking process. When they [patients and caregivers] begin to be involved with palliative care really, what are their wishes? And then finding out really, you know how dependant that person is on them, or they are on the person. And thinking about the future. I think it still has utility...so for us to then to be able to use, even if it's a couple of questions, to say 'oh you know obviously you are in the terminal phase, how do you think you may cope after?' or 'are there any issues for you?' Or you know, do we identify that they are particularly socially isolated and that they don't have anybody? Those groups of people that I think it would be a value for.

***Requirements for the measure to have potential for future use.*** It was considered that staff education would be needed, whether the GABA remains in its present form to be handed to some caregivers, or modified as a staff conversational assessment:

I think to roll out the form, even if the form was given to clinicians to give to family members, they would still need some education. I can't see that it's a form that's going to be given in general by all and sundry.

Education would also be required to have potential for use in the dying pathway and the referral process to the palliative care service:

Definitely I think a greater understanding of the fields within the questionnaire, and then if we were able to make a shortened more prompt questionnaire for professionals. That they had a real good understanding of why it was that those specific questions and what those fields were actually hoping to elicit from the family; to identify them as having bereavement issues after.

## Discussion

The data derived from the evaluation of the pilot of the GABA measure provided further insight into the bereavement risk assessment issues as they relate to palliative care that need consideration. The pilot proceeded very differently at each of the services; the services each reflecting a different model of palliative care delivery. This highlights the different issues between service types that need to be taken into account if a successful bereavement risk assessment model is to be achieved. The original intention had been to trial the GABA measure on 20 family caregivers at each of three different palliative care service models of care: a community domiciliary service; an in-patient unit; and a consultative service in an acute hospital.

**Problems Encountered in the Study.** When the pilot had been ready to proceed in October 2014, the management at the in-patient unit requested that the participant information sheet state more explicitly to caregivers that the staff would be reviewing the information on the measure in order to ascertain their bereavement needs. This amendment required approval from the three HREC bodies involved before the unit's hospital board gave its approval for the study some five months later. In the meantime the community service commenced the wind-up of its domiciliary service which resulted in only two caregivers participating in the assessment protocol at that site. Because data were not collected from more community caregivers, an opportunity was missed to map bereavement risk assessment in this setting.

Likewise only three caregivers were recruited from the in-patient unit which resulted in a lack of information as to how a bereavement risk assessment model would work in this type of service model. However, the staff feedback from the focus group was invaluable in highlighting some of the issues that need to be managed if bereavement risk assessment is to become routine practice in an in-patient setting. The data from the health professionals' focus group indicated there had been misunderstandings about the study in spite of having had numerous discussions and email correspondences with management and four information sessions for staff.

One contributing factor to the misunderstandings, suggested by the Clinical Nurse Manager, was that the documentation required by the HREC bodies was too long and involved to be scrutinised and readily understood. Although management requested changes to the participant information sheet so that caregivers would be

aware that the staff would be reviewing their responses to the items on the measure, the staff members approached by the researcher to review the completed measures were unwilling to view the information stating that they were already aware of how the caregivers in question were coping. There was also discomfort about how they might deal with the GABA document given it did not relate to the patient's care and medical file.

**Contact with Caregivers and Optimal Conditions to Administer the Measure.** Without staff involvement in the assessment process, finding caregivers by the bedside proved difficult during the researcher's visits to the unit. Management had requested that families of patients in the terminal phase not be approached. Finding family members present had also been problematic at the consultative service where patients are located across various departments that palliative care staff visit, but do not deliver direct care themselves. The consultative team quickly realised that the optimal time to administer the assessment was during times when the patient received nursing care when caregivers were away from the bedside. This approach minimised the need for caregivers to take additional time away from the patient to complete the assessment. Encroaching on precious family time was something the consultative team was keen to avoid. Assessment of caregivers during nursing care of the patient may have worked well at an in-patient unit given palliative care staff deliver care 24 hours per day and would have numerous opportunities to ask caregivers to complete the assessment during patient care.

**Bereavement Risk Assessment Practice: Maintaining the Status Quo.** The Physician in the focus group at the in-patient unit believed that building a family picture over time based on the multidisciplinary team opinion was the *gold standard* for assessment which may somewhat explain staff reticence to engage in an alternative assessment process. Such thinking was reflected in the earlier reference group discussions where the health professionals held that multidisciplinary team judgement was the mainstay to assessment of caregiver needs (Sealey, O'Connor, Aoun, et al., 2015). However, recently there has been an indication that patients and their families are referred to palliative care nearer end-of-life making it difficult for staff to build the comprehensive family picture they did previously (Agnew et al., 2011). Indeed, this pilot found that almost half the patients and families (47%) had been under the care of a palliative care service for less than a week, indicating that the addition of a self-

report assessment would be valuable in helping staff identify caregiver needs more quickly.

**Bereavement Risk Assessment Practice: Benefits of Change.** In contrast to the findings from the in-patient unit, the Clinical Nurse Consultant at the consultative service found the GABA measure useful in facilitating conversations between staff and caregivers which enhanced their ability to become familiar with patients and family. Moreover, she said that the assessment also provided a means by which staff could dispel people's misunderstanding and fears, thus reflecting the benefits of holistic palliative care involvement. The Clinical Nurse Consultant suggested that the GABA assessment could have a role in documentation, such as end-of-life pathways and Advanced Health Care directives. The use of such documentation promotes a comprehensive and unified approach to care by the palliative care multidisciplinary team and is regarded as being a key indicator of quality end-of-life care (Brown & Vaughan, 2013). As reported by the consultative service, end-of-life discussions are distressing for staff and families. Brown and Vaughan acknowledge that such distress regarding end-of-life conversations is commonplace in palliative care; however, the use of written documentation clarifies issues, leads to greater understanding, and lessens anxiety for staff, patients and family members. Documentation empowers people by fostering patient/family autonomy and ensuring patients and families remain central to decision making. Additionally, the use of documentation such as care pathways improve care and coordination of services and result in improved outcomes for clients. Such documentation allows clinicians to direct their attention to other essential clinical activities (Faber, Grande, Wollersheim, Hermens, & Elwyn, 2014).

**Consumer Friendly: Person-centred and Family-centred Care.** In improving quality health service provision, standard two of the Australian National Safety and Quality Health Service Standards promote an active consumer-centred, person-centred, or patient-centred approach to the delivery of services. Empowerment of patients and caregivers leads to improved outcomes for health service clients as well as more economical operational costs and greater workforce satisfaction (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011).

Patient-centred and family centred-care, guided by client values, is responsive to individuals' needs and moves away from the paternalistic doctor-centred service

provision of the 1970s and 1980s towards partnerships, information sharing and respectful collaboration (Bell, 2013; Faber et al., 2014). As Faber and colleagues suggest, such patient-centred care requires a shift away from health professionals' judgements to patient and caregiver involvement and consultation. While the move toward person and family centred practice is a goal of health service delivery (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011), it has not been generally implemented in practice, as Bell (2013) asserts, due to the beliefs of health care providers that they have the expertise and knowledge that patients and families lack. Other impediments to the practice of person-centred care relate to beliefs by health professionals that, as a concept it is idealistic, it undermines established service delivery models, and therefore is unworkable in clinical settings (Kirkley et al., 2011). These authors state that organisational culture also plays a major role in the delivery of person or family-centred care where priority may be focused on the needs of the service, rather than the needs of patients and families, and where the monetary cost of service delivery may be a factor for not effecting change.

**The Way Forward: Conversations to Enhance Family-centred Care.** The way to promote person and family-centred care is for staff to initiate conversations with family caregivers. Research shows that therapeutic conversations are beneficial for both staff and families; for staff, the conversations increase their understanding of the families they are caring for; while families experience greater emotional support and feel valued and heard by staff, particularly as their responsibilities and burden increases as the patient nears end-of-life (Bell, 2013; Halldórsdóttir & Svavarsdóttir, 2012). The Clinical Nurse Consultant at the consultancy service suggested that a modified version of the GABA assessment, reworked into a conversational protocol, would be useful for the many family caregivers who are unable to complete a self-report assessment, or who were unable to engage in assessment for cultural reasons. She highlighted that the majority of their caregivers were struggling to come to terms with the idea that their loved one was approaching end-of-life and that they would soon be bereaved.

While the Chaplain at the in-patient unit was also keen to have a bereavement risk assessment protocol in place that could be used by all multidisciplinary team members, it emerged that there were concerns by staff about the possibility that assessment would increase staff workloads. However, at the consultancy service they

had identified that in the cases where the GABA measure had been used, the assessment helped identify those borderline caregivers who they may have previously been uncertain about, and furthermore, the assessment clarified the follow-up support that might be most appropriate for individuals at the weekly team meetings. In effect, the use of the measure saved time and reassured staff that they were identifying those in need of support which they may not have otherwise recognised, given they do not have around the clock contact with families.

**Defensive Practice: Fear of ‘Opening a Can of Worms’.** The consultative unit staff believed the use of the measure helped guide their responses to identified caregiver needs; however, the in-patient unit staff members were concerned that identifying caregivers’ needs would “open a can of worms” and create legal obstacles. A question pertaining to suicidal ideation was particularly troublesome, with fears that if identified there would not be a process in place to ameliorate caregiver risk. Likewise, an item relating to the possibility the caregiver’s health might be suffering because of their care role also caused consternation as to how the service might be expected to respond. The Clinical Nurse expressed concern that inexperienced nursing staff would not be equipped to deal with caregiver responses to the GABA’s items, while the Clinical Nurse Manager believed that staff would need to take action and sort out caregiver problems which would take up valuable staff time that should be spent on primary patient care.

Such defensive practice has been found to occur when practitioners are concerned that litigation may be a consequence of perceived mismanagement and, as such, prioritize towards self-protection than what may best serve the needs of the patient or family (Mullen, Admiraal, & Trevena, 2008). Findings by these authors suggest that defensive practice has been found to be more commonplace in mental health settings because of emotionally charged issues such as suicide. Observation and judgement of client behaviour is likely to be used more than what would otherwise be considered clinically useful in other situations; however, the use of best-practice guidelines would lessen the need for defensive practice.

As Bell (2013) states, staff who are afraid of ‘opening a can of worms’ by becoming involved with families fail to establish rapport and restrict the possibility of conversations that might otherwise lead to improved outcomes for families. When staff

members are busy, communication with family and patients becomes task-orientated rather than person-centred (Ross et al., 2015). Research by Kirkley and colleagues (2011) shows that staff who are comfortable with present work routines, or alternatively who feel overwhelmed by present work schedules, or who believe that resources are insufficient, are unlikely to consider change in practice, particularly if the organisational culture does not support person or family-centred values. However, critics suggest "...that the nursing profession needs to look beyond the claim of staff being too busy (short staffed) or poorly resourced to provide PCC [person-centred care]" (Ross et al., 2015, p.1229).

**The Need for Education to Effect Change in Bereavement Risk Assessment Practice.** The health professionals at both services identified a need for education on grief and bereavement as well as education for conducting conversations with patients and family caregivers. Research conducted by Guldin, Vedtsed, Zachariae, Olesen, and Jensen (2012) examining the predictive ability of present bereavement risk assessment by palliative care health professionals to match need with targeted support found that "...the professional assessment was no better than flipping a coin" (p.1683). The authors assert that the reasons for problems with risk assessment in clinical settings may be, (apart from the need for a standardised measure), due to a lack of knowledge, given research on risk factors and/or bereavement complications lacks concordance; as such, they recommend that staff require support in order to perform bereavement risk assessment as a matter of course.

As discussed previously, referral pathways to existing community services also need to be established given palliative care resources and focus should be primarily directed towards patient care (Sealey, O'Connor, Aoun, et al., 2015). Education would be essential to ensure caregivers were referred to the appropriate services given the earlier reference group health professionals expressed reluctance to refer caregivers to other health professionals fearing referral might increase caregiver distress.

In short, the consultative service found positive aspects to administering a caregiver self-report in tandem with their usual observational means of identifying caregiver follow-up needs, following the patient's death. The measure seemed acceptable and easy to use by the majority of caregivers, however, wording relating to the patient's death and impending bereavement for the caregiver was deemed



confronting for many caregivers. Major barriers to using the self-report measure stemmed from caregivers' lack of readiness for the death of their loved-one and, as such, they were unable to comprehend that they might soon be bereaved. Similarly, cultural sensitivity limited discussion about dying and speaking of the patient as deceased, as well as the problems with assessment for those who have English as a second language and who require translation services. On the other hand, the measure was found to be useful in helping staff identify caregivers' needs and negated some uncertainty about follow-up. In spite of the barriers, the consultative service saw potential for ongoing use of the measure. However, the measure would have greater utility if also adapted to a staff conversational protocol and would have a possible role in pathway and advanced care planning documentation.

Staff at the in-patient unit did not engage in the assessment process, and the focus group evaluation showed that there was reluctance in relation to change in practice, uncertainty and confusion in relation to conducting the assessments and how to store the information, as well as apprehension about responding to caregiver needs identified by the measure. Whether resistance at the in-patient unit stems from defensive practice; an out-dated paternalistic approach to care (rather than embracing a person-centred approach); organisational culture; a lack of knowledge by health professionals about grief and bereavement; or a reluctance to refer caregivers to support services (Powazki et al., 2014; Sealey, O'Connor, Aoun, et al., 2015) as discussed in Chapter Five remains uncertain.

What was identified by both participating services as being essential, if change in practice is to be effected, is the need for education which has also been supported by earlier research (Powazki et al., 2014; Sealey, O'Connor, Aoun, et al., 2015). However, as the Clinical Nurse Manager of the in-patient unit stated, the application of a bereavement risk assessment protocol is "...not a five minute change to practice." Indeed Bell (2013) says that the dissemination of innovative practice takes 17 years.

**Strengths and Limitations of the Evaluation Phase of the Study.** Participant numbers were very small in this study and, as such, findings on acceptability or feasibility for use of a bereavement risk assessment protocol cannot be generalized to the wider population of caregivers. The caregivers in this study were selected by palliative care staff as being appropriate (or to have the ability) to engage in the self-

report assessment. The sample was made up predominantly of women (73.6%) from White European backgrounds. As a result, it is not known how such an assessment might be acceptable to caregivers from culturally, linguistically or religiously diverse backgrounds, nor does it indicate an optimal period in the caregiving trajectory during which an assessment might be best administered. Additionally, the withdrawal of the community domiciliary service and the lack of engagement of staff in assessment at the in-patient service resulted in insufficient data for comparisons between settings. There may be differences in the ways a bereavement risk assessment model could be applied in different palliative care models of service delivery.

The strength of this phase of the study lay in the health professionals who participated in the evaluation. They represented a range of designations that would typically make up a palliative care multidisciplinary team, each with considerable years of service in palliative care; as such, their opinions of the issues in relation to the feasibility of bereavement risk assessment in the clinical setting provides valuable data for further planning and research.

## **Conclusion**

The results of the evaluation of the trial of a bereavement risk assessment model indicate that a brief caregiver self-report may be acceptable to caregivers caring for a patient in a palliative care service. However, there is reticence on the part of staff members to administer the measure to all caregivers, particularly those for whom the patient has moved quickly from illness to end-of-life, or for those with cultural or linguistic diversity. Nor has this pilot indicated an optimal time frame to administer such an assessment during the caregiving trajectory. The measure helped staff make decisions as to the follow-up required, and has provided a point of conversation to get to know the families more quickly and facilitate conversations about palliative care. For this reason, a measure may have utility if modified as part of a conversational process for staff to use in situations where caregivers are not able to complete a self-report, and a measure may possibly have a role in care pathways and Advanced Care Planning documentation.

However, the pilot has also highlighted a number of major issues relating to bereavement risk assessment in palliative care that will need to be overcome. The primary concern relates to legal responsibility. Documentation may be an issue for

some services given the caregivers are not clients of the service and do not have a medical record. Services concerned with the provision of support if assessing a caregiver need or risk will need to review policies and procedures. However, one solution, suggested by Rumbold and Aoun (2014), would be to develop a triage or referral pathway to service providers external to their own service. By meeting such challenges palliative care services would be more aligned with accreditation and standards requirements (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011), and may find that assessment lessens staff workloads thus allowing them to focus on care of the dying. Assessment should also provide staff with some reassurance that caregivers are having their needs met appropriately. However, education about grief and bereavement, sensitive conversations with caregivers and medico-legal issues will need to be part of an ongoing process.



## **CHAPTER EIGHT**

### **Discussion**

“Every new beginning comes from some other beginning’s end.” – Seneca

#### **Chapter Overview**

Chapter Eight concludes the thesis with a discussion on the contributions that this research has made to the empirical literature, clinical practice, and policy. The use of action research is also discussed. The many complexities relating to bereavement risk assessment found throughout the research are presented in terms of moving forward towards a bereavement risk assessment model in the future. Suggestions are proposed for overcoming many of the barriers and maximising the facilitators to change. Limitations of the study are outlined and the direction for future research is detailed.

#### **Introduction**

Given the adverse health and poor bereavement outcomes that may result for a minority of individuals at risk of complicated or prolonged grief (M. Stroebe et al., 2007), assessment of bereavement risk remains a priority in palliative care so that caregivers can be linked with appropriate support in a timely manner (Hudson et al., 2010; Palliative Care Australia, 2005b). The aim of this research study was to develop a bereavement risk assessment model feasible for use in palliative care.

Action research was chosen as an overarching methodology in anticipation that if palliative care stakeholders had a voice in the study, the bereavement risk assessment model would have greater feasibility and sustainability in clinical practice (Hart & Bond, 1995). Action research is a dynamic and iterative process of problem-solving and action-taking to effect change, and is carried out in collaboration with stakeholders (Baum et al., 2006; Waterman et al., 2001). As such, research activities are context-specific (Waterman et al., 2001) and develop in response to information gathered in earlier cycles (Hockley et al., 2013. Refer Chapter Three). Action research provided an ideal methodology that was responsive to the challenges encountered in working in palliative care. An initial research plan was established at the outset of this study and,

in response to stakeholder input, each phase built upon findings from the previous phase.

The development of a new measure had not been part of the original research plan but was introduced in response to reference group advice (see Chapter Five) when no existing grief measures were found suitable for palliative care use (see Chapter Four). The new measure was based on known risk factors for complicated or prolonged grief (Lobb et al., 2010) and developed in consultation with bereavement service providers and bereaved former caregivers (see Chapter Six). The measure was then piloted at three different models of palliative care services (see Chapter Seven). As discussed in Chapters Six and Seven, a number of obstacles were encountered including the closure of one participating service and difficulties in engaging the health professionals at another service. Evaluation of the utility and feasibility of using a caregiver self-report assessment in clinical practice yielded valuable information that will be useful in future research and planning, such as the development of a comprehensive framework for pre-death caregiver assessment and the provision of bereavement support.

## **Overall Contribution of the Study's Findings**

This research has delivered a number of important outcomes providing much-needed and valuable information to guide clinical practice, policy and future research. The research study has made contributions to the field of bereavement risk assessment in terms of augmenting the empirical literature, informing clinical practice and policy, and the innovative use of action research methodology in clinical assessment.

## **Contribution to the Empirical Literature**

**Scoping review of the literature: key findings.** The scoping review of the literature to identify existing grief measures (Sealey, Breen, et al., 2015) highlighted the shortage of existing grief measures suitable for use in palliative care (M. Stroebe & Boerner, 2015). The review gathered a comprehensive list of grief measures and was the first to categorize the measures for possible use at various points along the caregiving and bereavement trajectory; additionally, the measures were considered in the context of feasibility for palliative care clinical use. The present scoping review supports previous findings by Agnew, Manktelow, Taylor and Jones (2010) who

examined 10 measures in detail and who likewise found that some measures did not differentiate between normal or complicated grief responses, and some lacked theoretical or psychometric validity and reliability evidence. Some of these measures, identified by Agnew et al., also relied on staff observation, rather than direct enquiry or caregiver self-report.

### **Strengths of the Scoping Review of the Literature**

The scoping review of the literature provided a major contribution to the empirical literature on assessment of bereavement risk (M. Stroebe & Boerner, 2015) highlighting that, while there was no shortage of psychometrically sound grief measures, the measures that might deliver clinically useful information in light of current understandings of grief responses were impractical to use in palliative care settings (Sealey, Breen, et al., 2015. Refer Chapter Four). A strength of the scoping review was that it systematically mapped grief measures, rather than a variety of other palliative care measures, across the caregiving trajectory and into the period following bereavement; and moreover, in relation to applicability to the unique circumstances relating to palliative care clinical settings.

**Collaboration with palliative care stakeholders: key findings.** A number of problems with assessment related to contact with caregivers following the patient's death, which directed assessment to the patient's pre-death care period (Sealey, O'Connor, Aoun, et al., 2015. Refer Chapter Five). Given potential benefits to caregivers by early identification of bereavement needs (Zhang, El-Jawahri, & Prigerson, 2006), focusing on the patient's pre-death period for assessment of caregiver bereavement needs warrants closer examination (M. Stroebe & Boerner, 2015). M. Stroebe and Boerner suggest there are a number of unanswered questions in relation to assessment prior to the patient's death. Such questions include: the type of assessment that might be clinically useful and acceptable to caregivers and staff; the type of assessment that might meet caregiver needs and lessen burden of care to positively influence bereavement outcome; the type of assessment that would be achievable and sustainable in practice; and if such an assessment might accurately target those in need. Discussions with palliative care stakeholders across the various phases of the study were conducted during the present research and provided valuable insight that helps move towards answering these questions.

***Acceptability of an assessment protocol.*** This research found that the use of a self-report grief measure was acceptable to caregivers and assisted staff by facilitating conversations about the patient's end-of-life and support needs of the caregiver. Staff also found it helpful in decision-making regarding follow-up support after the patient's death. The health professionals suggested that the assessment could be extended in two ways: to include a staff-administered assessment, and to become part of advance care planning and care of the dying documentation (see Chapter Seven). The present research also found that an assessment protocol can be accepted as routine practice, particularly if supported and championed by a team member.

As found in the reference group and focus group data, palliative care health professionals prefer to assess caregiver grief needs based on their own professional expertise and judgement (Sealey, O'Connor, Aoun, et al., 2015. Refer Chapters Five and Seven). The addition of an assessment measure completed by the caregiver, rather than based on observation and intuition of staff, will add valuable information to assist the multidisciplinary team in decision-making regarding the provision of grief support following the patient's death.

***Clarity of assessment: Constructs, domains, and nomenclature.*** To achieve a practicable assessment model, palliative care health professionals first need to be clear about what domains or constructs they are assessing so that appropriate responses can be put in place (Sealey, Breen, et al., 2015). The reference group data in the present study showed there was some conflation between caregiver stress, burden and grief and health professionals were uncertain of what to assess and how to respond to the assessment or screening accordingly (Sealey, O'Connor, Aoun, et al., 2015). Part of the uncertainty may stem from the complexity of stressors faced by caregivers as end-of-life approaches (Guldin et al., 2012), where staff respond to caregiver exhaustion or worries in relation to care for a family member who is dying (Doka, 2014). Doka (2014) suggests that health professionals who care for dying patients and their families tend to form strong bonds, which may influence their interpretation of caregiver emotional states or needs. Uncertainty in interpreting caregiver emotional reactions may also arise from staff misunderstandings about grief processes and terms used for grief responses (Deffner & Bell, 2005).



Over the past two to three decades research has increasingly focused on grief and bereavement, which has resulted in greater understandings of the processes and outcomes of bereavement; empirical studies show that a minority of people experience complex grief responses and criteria have been offered for diagnostic classification systems (Prigerson et al., 2009; Shear et al., 2011). While many clinicians and researchers have debated the idea that grief might be viewed as pathological by taking this view (Knoll, 2012; Rosner, 2015), few would challenge that there are a small number of people distressed by grief who would benefit from timely support (Boelen & Prigerson, 2013; Brocklehurst, Hearnshaw, & Machin, 2014).

Indeed, discourse on the nomenclature for complicated or prolonged grief has been challenging throughout this study when focusing on assessment in order to provide support for those at risk of poor bereavement outcomes. Lobb and colleagues (2010) have previously noted the confusion experienced by health care providers from the variety of terms used and the many conceptualizations of complex grief. Complicated Grief (Shear et al., 2011), Prolonged Grief Disorder (Prigerson et al., 2009), or Persistent Complex Bereavement Disorder as per classification in the present *Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition* (DSM-5) (American Psychiatric Association, 2013) are only applicable terms when people meet diagnostic criteria at a specific timeframe following a loss through formal clinical assessment by qualified practitioners. Using the same diagnostic terms to describe the situation of a group of people at potential risk of poor bereavement outcomes due to having identified risk factors prior to the bereavement event is both inaccurate and unhelpful in that it may shift the focus of attention from follow-up support to formalized diagnoses in need of treatment.

In accordance with the public health model (Aoun, Breen, et al., 2012) only a small number of people might be eligible for a formal grief diagnosis in need of professional intervention, which could only be established long after palliative care services have concluded their bereavement services. This was identified by the reference group members (Sealey, O'Connor, Aoun, et al., 2015). The use of diagnostic terms pre-death is also irrelevant and misleading for those in a medium risk category who require some additional assistance such as a support group (Aoun, Breen, et al., 2012). It is also possible that the focus on a grief diagnosis twelve months following a death may de-emphasize the importance of identifying those caregivers with present,

co-morbid depression or anxiety due to their caregiving role (Boerner & Schulz, 2009; Guldin et al., 2012; Hudson, Thomas, et al., 2011), and who may benefit from earlier intervention to avoid a grief diagnosis in the future. What is required is a separate term (different to any current diagnostic term) to describe the situation of those individuals at risk of complex or maladaptive responses, which might be triggered by the bereavement event, so that confusion about the construct can be minimized.

While much more is known about complex grief responses due to intensive research in the area (Prigerson et al., 2009; Shear et al., 2011), it is possible that palliative care clinicians have not kept up-to-date with current understandings of grief responses, which may affect their ability to engage in assessment. Research shows that many health professionals lack up-to-date education about grief and grieving processes (O'Connor & Breen, 2014; Powazki et al., 2014); indeed, it would seem many university courses do not adequately educate health professionals to provide appropriate responses to grief (Breen et al., 2014). The need for education for palliative care staff in relation to bereavement risk assessment was highlighted by both the in-patient and consultative services during the evaluation of the bereavement risk assessment model, and would be required if implementing a risk assessment model in future.

**Multiple domains of caregiving in palliative care.** While a few literature reviews have been conducted investigating instruments suitable for caregivers for use in palliative care, the instruments reported have covered a variety of domains. For example, in a review by Hudson and colleagues (2010), the caregiver instruments covered domains such as: satisfaction with care of the patient; mental health issues (e.g. depression or anxiety); perceived satisfaction or quality of life; perceived support needs; burden or social impact of the caregiving role; perceived preparedness for the coming death; family functioning; as well as five grief measures. Mularski and colleagues (2007) also conducted a literature review to identify instruments measuring outcomes of end-of-life care which included 10 grief measures among many other domains. These examples demonstrate the complexity of issues faced by palliative care healthcare professionals in relation to identifying multifaceted caregiver support needs, indicating why conflation between caregiver stress, burden and grief might occur. This highlights the need for greater clarity around assessment.

**The caregiving trajectory: Pre-loss and post-loss.** To date little attention has been directed towards the caregiving trajectory in its entirety, from prior to the patient's death to post-death and beyond (M. Stroebe & Boerner, 2015). There is evidence to suggest that caregivers who have cared for a significant other throughout a life-limiting illness are adversely affected during bereavement due to their caregiving role (Boerner & Schulz, 2009; Guldin et al., 2012; Hudson, Thomas, et al., 2011). Increases in chronic illness, such as cardiovascular disease, dementia, and other chronic organ failure disorders, in developed nations, point to the increasing need for palliative care services for this population, and support for the caregivers who are at risk of poor bereavement outcomes as a result of caregiving (Boerner & Schulz, 2009). Caregivers are often thrust into this physically and emotionally demanding role without preparation or training, and as a result, may suffer increased distress such as anxiety or depression where "...the psychological burden of the caregiver exceeds that of the critically ill patient" (Williams & McCorkle, 2011), p.324). Research shows that many family caregivers of terminally-ill patients experience higher rates of depression and anxiety, with elevated levels of complicated grief symptoms present in more than a third of caregivers at six months post-loss, with only slight decreases in numbers at 13 months after the death (Thomas et al., 2014). Palliative care services are therefore ideally situated to assess caregiver bereavement needs prior to the patient's death so that caregivers at elevated risk might be linked with appropriate support (Boerner et al., 2013; Kelly et al., 1999; Zhang et al., 2006).

**Benefits of directed assessment for caregivers.** As discussed previously, the Carer Support Needs Assessment Tool (CSNAT) (Ewing & Grande, 2012) which directly enquires about caregiver needs during the caregiving period, has been trialled in palliative care (Aoun, Grande, et al., 2015; Ewing et al., 2013). This research showed that identifying caregiver needs resulted in timely intervention and led to reduced caregiver strain. Similarly Schulz and colleagues (2006) found that easing caregiver burden during the illness had positive benefits in lessening poor bereavement outcomes. There were also benefits to the assessment of caregivers for the health professionals in the present research. They found the tool useful as it provided a focus to assessments, thus facilitating discussions with caregivers and it helped in developing relationships with family members (Aoun, Toye, et al., 2015). These findings demonstrate the many advantages to be gained for staff and families by engaging

caregivers in direct assessment; guiding the way to assess risk of poor bereavement outcomes more effectively and leading to timely intervention.

### **Contributions to Palliative Care Practice, Policy, and Standards**

The recently developed *Bereavement Support Standards for Specialist Palliative Care Services* (Hall et al., 2012) have been invaluable as an initial step in guiding palliative care services to move from informal observational assessment of caregivers toward systematized and documented assessment. Data from the scoping review (Chapter Four), reference group (Chapter Five) and evaluation phases (Chapter Seven) indicate that some of the standard's recommendations are incongruent with what is feasible to deliver in clinical practice and, as such, are in need of addressing.

Such standards are essential in healthcare in order to provide access to, and safeguard, optimal practice in the delivery of quality health services; as such, they should be directed to those areas of high-priority where gaps exist and there is a substantiated need for intervention (Brand, Ibrahim, Cameron, & Scott, 2008). Brand et al. (2008), state that standards should encompass stakeholder agreement as, without such agreement on minimally accepted procedures, there will be confusion and a lack of robust measurable outcomes.

**Bereavement standards: Pre-death assessment.** The bereavement support standards (Hall et al., 2012) recognize the lack of any one appropriate screening tool and suggest "...a structured assessment should be undertaken through a conversational exploration of risk factors and strength/resilience factors" (p.11). They add that this should be documented and reviewed by the multidisciplinary team. The standards also recommend that caregiver assessment should commence as soon as practicable after the patient's admission and should be ongoing throughout contact with the service. However, the present study highlights difficulties with some aspects of the application of such standards in practice.

**Practice: Barriers to pre-death assessment.** The reference group data show that staff members would prefer to have informal conversations as an aside at the door or on the way to the car, and prefer to use clinical judgment rather than caregiver self-report (Sealey, O'Connor, Aoun, et al., 2015). This is incongruent with structured and documented assessment. Previous research has also indicated that many health

professionals are uncomfortable having such sensitive discussions (Deffner & Bell, 2005) preferring informal conversations to standardized or consistent protocols (O'Connor & Fisher, 2011). Staff members can be challenged by caregivers' grief reactions and often experience apprehension when communicating with family members, particularly when there is family conflict which tends to escalate due to anxiety at end-of-life (Del Gaudio, Zaider, Brier, & Kissane, 2011). The evaluation phase of this study found that assessment was perceived to affect work schedules, and staff considered they have no time to administer the assessment. These were contributing factors in not undertaking caregiver assessment (Davis et al., 2003).

The reference group members also believed that assessment on admission to a palliative care service would be too overwhelming for caregivers, given the rapid changes that may have occasioned the patient's admission to the service (Sealey, O'Connor, Aoun, et al., 2015). In evaluating the assessment process at the consultative service, it would seem that many caregivers were too stressed to complete a pen and paper assessment when the patient for whom they were caring had recently been deemed in need of palliative care. As discussed in Chapter Seven, many caregivers were struggling to come to terms with the idea that their loved one was about to die and, as such, the caregivers were not thinking ahead to the possibility that they would soon be bereaved. The caregivers were also unsure of the meanings behind the items on the measure and how to respond to them. The in-patient unit staff members were unwilling to add to caregiver distress by asking caregivers to complete an assessment while the patient was in the terminal phase, and the consultative staff members were concerned that they might take away from families some precious time with the patient in order to complete a brief assessment. It would seem from these findings that there is an optimal window prior to the patient's death to assess caregiver bereavement risk and further research is needed to narrow that time frame.

**Bereavement standards: Post-death assessment.** The bereavement standards note the difficulty of making predictions about a caregiver's longer-term function or likelihood of prolonged or complicated grief reactions (Hall et al., 2012). The standards also recommend that the degree of trauma in response to conditions around the time of death be assessed as soon as possible following the patient's death, but give no guidance on the method this assessment would take. Additionally, it is suggested that all caregivers should be followed-up by telephone at 12 weeks after the death.

Those caregivers, who may have been assessed as being potentially at risk of complicated grief issues in the initial assessments and shortly after the death, should be contacted at approximately six months and assessed with a validated tool such as the PG-13. Indeed, Thomas and colleagues (2014) have suggested the need to screen caregivers for prolonged or complicated grief a year following the death, given that their research found only slight decreases in numbers of people with complicated grief symptoms at 13 months post-death; however, they noted the problems for palliative care services in assessing for, or providing support at that time. This is consistent with the findings from this present study which found that bereavement follow-up is limited to the weeks following the patient's death due to funding and staffing constraints (Sealey, O'Connor, Aoun, et al., 2015). According to the standards, at any time throughout the caregiving and post-death period any caregivers indicating they have elevated risk, or who may be suicidal, should be urgently referred to an emergency service.

**Practice: Barriers to post-death assessment.** Indeed the findings from the present study raise several difficulties with the standard's suggested assessment protocols:

*Contact with caregivers.* One substantial barrier identified by the reference group (Sealey, O'Connor, Aoun, et al., 2015) related to having contact with caregivers following the patient's death. Most services do not have face-to-face contact with caregivers at this time, and rely on telephone conversations to follow-up family members.

*Communicating with caregivers.* Many staff members are not comfortable communicating with grieving family members, which may be due to a lack of appropriate training (Deffner & Bell, 2005); moreover, palliative care health professionals tend to shun formal assessment procedures (O'Connor & Fisher, 2011). Communication via telephone is also difficult for time-poor staff members who are taking on bereavement follow-up as an additional role. This is exacerbated by a lack of funding or having no bereavement officer skilled in assessment. Additionally, many palliative care services' bereavement programs are time-limited due to funding and staffing constraints and cannot provide ongoing bereavement follow-up and support following the patient's death (Sealey, O'Connor, Aoun, et al., 2015).

***Supporting caregivers: services and referral pathways.*** The reference group (Sealey, O'Connor, Aoun, et al., 2015) and focus group evaluation data from the present study also highlighted that service personnel perceived a lack of support services to meet assessed needs. Assessment applied in the absence of a support response may increase caregiver distress (Snowden et al., 2011). Focus group participants from the in-patient unit were concerned that if they assessed a need they would be required to respond and would not have the resources to do so; whether that was having the time for staff members to discuss caregiver concerns, or providing a formal response to risk such as in the case of suicidal ideation or self-harm. However, health professionals need to move away from the prevailing idea that they are best placed to provide caregiver support themselves (O'Connor & Fisher, 2011). The bereavement support standards exhort palliative care health professionals to be aware of their limitations and to be informed of referral routes should caregiver needs be outside the scope of their expertise (Hall et al., 2012); however, as noted by O'Connor and Fisher (2011), staff tend to be unaware of their limitations. As discussed previously, it would be worthwhile for palliative care services to develop referral pathways to programs offered by community bereavement service providers (Rumbold & Aoun, 2014), and it would seem logical that a triage pathway based on risk according to a public health model of bereavement support (Aoun, Breen, et al., 2012) should be reasonably straightforward to plan and implement. This mirrors findings from research in oncology using the Distress Thermometer and Problem Checklist to screen routinely for patient distress (Van Hoose et al., 2015). Several authors argue that this approach is only feasible if clear referral pathways are established (Snowden et al., 2011).

***Meeting support needs of caregivers.*** In Australia, initiatives to provide better outcomes in mental health care, available through a Medicare Benefits Schedule, have improved treatment rates for those who have access to such services, although youth, socio-economically disadvantaged individuals, and those living in remote areas have not accessed the scheme as readily (Pirkis, Harris, Hall, & Ftanou, 2011). Those caregivers potentially in the high risk category according to the public health model (Aoun, Breen, et al., 2012) are likely to have reasonable access to professional services if they are referred to such a service and are not disadvantaged by socio-economic status or location. However, for those caregivers in the medium risk group (according

to the public health model) who would be in need of some additional assistance such as a support group, there may be more variance in availability of appropriate quality services in individual communities. The support needs of this group warrants enquiry, so that community services can be targeted to their needs in order to prevent poor health outcomes.

### **Less Obvious Barriers to Assessment of Bereavement Risk**

The present study has also revealed less overt, but nevertheless substantial, issues that will need to be considered before a formal assessment of bereavement risk and provision of support can become part of routine practice in palliative care.

**Family caregivers as the unit of care.** Unlike most other domains of medicine, palliative care services have traditionally viewed family caregivers as part of the unit of care throughout the patient's illness and beyond death for bereavement support (McNamara & Rosenwax, 2010; World Health Organization, 2015). Other such situations occur in paediatric and intensive care units where family members may be required to make treatment decisions on behalf of the patient as proxies (Davidson et al., 2007). However, being family members rather than direct clients of the service may pose problems in regard to documentation, particularly in relation to treatment and consent after the patient's death.

**Documentation.** Disquiet was expressed during the bereavement risk assessment process at the in-patient unit in relation to generating and filing a caregiver assessment document when the caregivers were not clients of the service and did not have a medical record in which to file documents. This is at odds with the bereavement support standards which recommend structured documentation of risk assessment (Hall et al., 2012). Individual palliative care services should review their legal obligations in relation to information that is gathered from family members, how that information is used and stored, as well as how such records are maintained over time.

**Discrimination and stigma.** A report by the Mental Health Council of Australia (2011) found that many Australians experiencing mental health conditions encountered discrimination, and had considerable difficulties accessing insurance products or lodging insurance claims. Insurance products include life insurance cover, and are also connected to compulsory third party car registration, superannuation schemes, travel,



and private health cover. Similar findings were reached in New Zealand and Britain where implications for assessing a mental health issue also related to financial institutions and the impact on loans and mortgages. The report also found evidence of distrust between mental health providers and insurance providers, which exacerbated issues of accessing insurance. The Mental Health Council of Australia report (2011) highlighted the degree to which stigma pervades Australian society, which may affect an individual with a diagnosis of a mental health condition. Discrimination has been identified in a majority of workplaces (Australian Government, 2008). Should a caregiver agree to engage in bereavement risk assessment and eventually be diagnosed with a mental health condition such as depression, anxiety or persistent complex bereavement disorder (as defined in the present DSM-5, (American Psychiatric Association, 2013), as a result of the assessment, it is possible that there could be unexpected consequences such as stigma or difficulties accessing insurances or employment. For example if a caregiver was unable to access an insurance payout as a result of an earlier bereavement risk assessment undertaken without an understanding that the assessment may lead to a mental health diagnosis, it is conceivable that it could lead to legal action.

***Informed consent.*** Engaging in assessment therefore raises issues in relation to informed consent. The bereavement support standards recommend that caregiver consent be obtained to engage in assessment (Hall et al., 2012) and, indeed, Australian Government privacy laws in relation to health stipulate that sensitive personal information should not be collected without the individual's voluntary, informed consent; that is, the individual is aware of the implications of such a decision (Australian Government National Health and Medical Research Council Privacy Committee, 2004). At present the potential consequences of consenting to assessment should a mental health diagnosis result is uncertain and needs to be fully examined so that a sound assessment protocol can be developed that accounts for ethical and legal considerations.

**Person and family centred practice.** As discussed in Chapter Seven, in moving towards improved health service provision, standard two of the National Safety and Quality Health Service Standards endorses patient and family focused care (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011). However, the provision of caregiver bereavement support needs, based on present

assessment practices of observing and intuiting family members' needs (Sealey, O'Connor, Aoun, et al., 2015), is at odds with the provision of person or family centred care. It is possible that funding may become more directly linked than it is at present to compliance with such standards (Victorian Government, 2014). If this is the case, then these issues of documentation and ramifications in relation to mental health diagnoses will need to be tabled urgently by palliative care stakeholders; the workforce sector, policy makers and health service consumers.

In summary, the data derived from the reference group and evaluation meetings were invaluable in highlighting the many barriers and issues that need to be resolved before a bereavement risk assessment model can become standard practice in palliative care settings. The findings also pointed to ways in which present practice could be modified so that caregiver assessment might be achieved (Sealey, O'Connor, Aoun, et al., 2015). What became apparent from these discussions with stakeholders was that the period before the patient's death provided a prime opportunity to conduct caregiver assessments, whereas assessment following the patient's death posed problems for a number of reasons including the ability to contact caregivers to administer assessment via telephone. The complexity of these issues has been discussed in Chapter Five.

### **Methodology: The Contribution of Action Research**

Although action research is relatively new to research methods as a type of social enquiry (Hockley et al., 2013), it was chosen for this study so that palliative care stakeholders could actively participate and assist in developing a bereavement risk assessment model that would be feasible for use in clinical practice (Hart & Bond, 1995). Palliative care and action research have much in common. Both were developed in response to the limits imposed by dominant models of care and approaches to research, and they have a shared philosophy of holism that recognizes the individual within a greater social system (Froggatt et al., 2012). Action research, therefore, is an ideal research methodology for palliative care in that it encourages health professionals to assume responsibility for their clinical practice within their own workplaces (Ross et al., 2015), thus as Hockley, Froggatt, and Heimerl (2013) state, challenging the palliative care sector "...to take the necessary risks to look at our own practice and address assumptions in order that we can continue to strive for improvement in our care of people and their families facing the end of their lives" (p.2). In this respect

action research empowers stakeholders, and has the potential to lead to change for individuals and multidisciplinary teams at the organizational level, and at the systems level such as policy (Froggatt et al., 2012).

In spite of the synergy between action research and palliative care, and the benefits of using action research in palliative care, Hockley, Froggatt, and Heimerl (2013) have found a scarcity of palliative care projects using action research: the majority of the reported projects relate to care facilities and domestic homes where the research focus has not been on clients or users of direct palliative care services. The authors speculate that the reasons for not collaborating with palliative care or vulnerable populations such as the terminally ill may be due to the challenges of conducting research in palliative care such as recruitment issues, compliance and high attrition rates at end-of-life. These challenges have been well documented (Hudson, Aranda, Kristjanson, & Quinn, 2005; Lobb et al., 2010).

Hockley, Froggatt, and Heimerl (2013) state that because the focus of the research is about practice, is undertaken in collaboration with practitioners, and has the intention to change practice, action research is extremely complex. Given there are various ways of knowing, and that knowledge is a dynamic process in itself, Hockley and colleagues argue that the outcomes of action research should not be evaluated on change in practice, rather, on what has been discovered by going about the process of change. As such, action research can be extremely challenging due to its participatory nature, and it can be concluded that the greatest challenges arise at the intersection of both action research and palliative care, and may arise from a variety of sources: relational factors between participants as collaborators; issues of power; initiating and maintaining participation; and the process of change itself in clinical practice (Froggatt et al., 2012).

**Relational factors and issues of power.** Central to action research is the need for relationships between researcher and participants in order to bring about change (Froggatt et al., 2012). Such relationships need time to be established in order to become productive otherwise organizational needs may determine the process (Gaventa & Cornwall, 2001). Even for ‘insiders’ (where the researcher is or was a part of the stakeholder group as was the case in the present study) a new role as researcher needs to be established so that blurred boundaries and issues of power are less likely to

surface (Froggatt et al., 2012). Such issues of power can occur at any time throughout the research. Due to the nature of action research and enquiry into practice, long held practices and hierarchies can easily be challenged and this may be seen as a threat to the status quo and people's positions held within the workplace (Froggatt et al., 2012).

**Participation.** The most important feature of action research is the quality of participation by the stakeholders, rather than the quantity of participation, where stakeholders who are committed to the research will be less likely to regard their part as an obligation (McIntyre, 2008). Indeed, participation by stakeholders is essential to generating the knowledge needed to inform the study and bring about any change in practice (Waterman et al., 2001). Participation between researcher and health practitioner participants may vary from a one-off or occasional encounter to a greater in-depth partnership throughout the term of the study and, while change in practice may sometimes be rapid, enthusiasm on the part of participants or management may decrease allowing previous practice to re-surface (Holter & Schwartz-Barcott, 1993). Participation by stakeholders in the present research was mixed, with a champion for the study driving the change at one service, while a lack of involvement and desire to retain previous ways of working was ingrained at the other service.

**Process of change.** Given the purpose of action research is to engender change in practice, there are likely to be a range of reactions to new ideas or processes which may result in conflict, particularly if management may not be able to support whatever outcomes arise from the research (Froggatt et al., 2012). The belief by management and staff at the in-patient unit was that the service would not be able to cater for the assessed needs of caregivers and would impose additional burden on staff.

### **Strength of Action Research as a Methodology**

The use of action research methodology has facilitated the many findings of the current study and collaborating with palliative care stakeholders has been a major strength of this research. The stakeholders have included health care professionals representing various job roles and a variety of service models of care from ward staff to management and bereavement service providers, as well as bereaved former caregivers and caregivers presently caring for a loved one. This broad variety of perspectives from service providers and consumers of such services has been

invaluable in mapping the complexity of bereavement risk assessment practice and showing the way forward for the future.

In summary, the use of action research in the present study was the optimal choice of methodology to examine current bereavement risk assessment practice and to attempt to develop a bereavement risk assessment model that would be feasible and sustainable in palliative care practice. While participation by stakeholders varied between services, and responses to the action cycle findings were divergent, the findings offered by the stakeholder participants have provided valuable information in mapping the barriers to and the facilitators of change for future practice. The problems encountered in the research process relating to lack of engagement and participation in the assessment protocol have clearly illustrated the problems to be overcome if a bereavement risk assessment is to be put into practice. This study has therefore highlighted how action research can benefit palliative care practice by working collaboratively with the sector to bring about change that is identified, mapped, and resolved by palliative care stakeholders themselves, so that change will be feasible and sustainable for the future.

### **Reflection, Reflexivity and the Researcher**

Following palliative care service provider consultations (Aoun, O'Connor, et al., 2012) prior to the commencement of this study, I was convinced that the timing was right to undertake this research (see Chapter One). I felt optimistic that collaboration with local palliative care services would result in the straightforward development of a bereavement risk assessment protocol that would be congruent with standards and policy (Hall et al., 2012), as well as an assessment protocol that would be feasible for use in clinical practice. On reflection on completion of the study, it was naïve to expect that a bereavement risk assessment model would be straightforward to develop and implement in practice. The unexpected findings and outcomes throughout the various phases of the research have provided an understanding of the many complex issues relating to bereavement risk assessment in palliative care, and will ultimately lead to a far more robust and practicable risk assessment model in future that will be sustainable in the longer term.

As discussed in Chapter One, a researcher has expectations of the study and its outcomes based on previous experience and, as such, his or her expectations influence

the research (Corbin & Strauss, 2008). As an ‘insider’ I had worked in palliative care for many years. I needed to balance my own outcome expectations against those of the stakeholder community (Lincoln, 2001). At times I found the disparity between what is known from the empirical literature and clinical practice to be challenging and it was difficult negotiating the various phases of the study.

In looking back through my reflexive journal, attendance at grief and palliative care conferences was instrumental in leading me to question my own biases and views when caught up in the challenges that occurred at various times throughout the course of the research. There were points along the way where the outcomes of individual phases were unexpected, and which required re-evaluation of the study. One such turning point occurred following the reference group meetings, where it was clear that stakeholders thought that a bereavement risk assessment model could not be developed using existing grief measures. Barriers to administering bereavement risk assessment were identified by the reference group members, and some of these barriers were, in my opinion, reasonably easy to overcome. For example a triage protocol and referral pathway for those caregivers identified as at potential for risk for poor bereavement outcomes could easily be put into effect tailored for each of the services. However, a triage protocol was rejected by the reference group health professionals as being too complex to be practicable. Some of the health professionals voiced disapproval of the use of a caregiver self-report measure in general, believing it would add to caregiver burden; others were concerned that caregivers would not be honest in their responses to the items, deeming it best to continue assessment of caregiver states using staff professional judgement.

I puzzled as to why the local palliative care service sector had so recently identified bereavement risk assessment as a high priority area (Aoun, O'Connor, et al., 2012). In March of 2014, I attended the *Australian Centre for Grief and Bereavement's* national conference where I presented the findings from the reference group collaboration. The response from the bereavement service sector was overwhelmingly positive in that a number of delegates said that addressing the issue of bereavement risk assessment, particularly in palliative care, seemed an onerous task and was a priority area in their own workplaces. These conversations gave me renewed energy to return to Western Australia and once more tackle the problem. The conference stimulated new ideas and I decided that caregivers themselves would be in the best

position to determine whether or not a caregiver self-report measure would be acceptable and this informed the next phase of the research. Overall, my reflexive journal has been a useful process to stimulate ideas, problem-solve and track the development of the study throughout its phases and changes.

### **Moving Towards a Future Bereavement Risk Assessment Model**

**Acceptability of a brief self-report measure: caregivers.** In attempting to develop a bereavement risk assessment model, a new brief grief caregiver self-report measure was developed. The caregivers in this small sample largely found using a brief self-report paper and pencil questionnaire acceptable. However, the caregivers were selected by staff as being suitable participants and considered to be coping well enough with their situation to handle completing an assessment. Many caregivers were deemed unsuitable by staff to engage in the assessment, as they were considered not to have come to terms with the impending death of the patient due to short length of patient stay. Because only two caregivers participated from the domiciliary service and three caregivers participated from the in-patient unit, the acceptability of completing a measure was not well tested on those caregivers who might already be at a stage where they were able to think about their own bereavement needs. As such, it is difficult to ascertain how the majority of caregivers might accept completing a self-report assessment across the board and needs further study.

As mentioned earlier, findings from this study suggest the period prior to the patient's death is the optimal period to assess caregiver bereavement risk. However, piloting of the new measure indicated that there were difficulties in administering assessment at this time due to caregivers not being ready to complete such an assessment, or being overwhelmed at the time of admission or at end-of-life. Staff members were also reticent to deprive families of precious time with the patient. The consultative service showed that the measure could be administered during patient care (such as hygiene or other procedure) when the caregivers were away from the bedside. This study has highlighted there is an optimal timeframe in which to assess caregiver bereavement needs; however, further research is needed to hone in on that period.

**Acceptability of a brief self-report measure: palliative care staff.** Evaluation of the health care professionals' views of using the risk assessment reinforced findings from the earlier reference group discussions in relation to some of the major barriers to

assessment, including a reticence by staff to change from observation and intuition of caregivers' needs based on professional experience at one site. However, the evaluation also highlighted that there were a number of positive aspects to assessment of caregiver bereavement risk and pointed to various ways that assessment assisted palliative care staff; for example by providing a means of initiating sensitive end-of-life conversations with caregivers, or helping decision making in relation to which caregivers may need support and the type of follow-up needed. The staff could also see application for a modified assessment as a conversational-based assessment and as part of dying care plan pathways and advance care planning documentation. Brown and Vaughan (2013) suggest that such pathways clarify treatment and planning options for both family members and staff, increase autonomy in decision-making and, as such, accord with principles of family-centred care.

The health professionals in one palliative care service were reluctant to engage in assessment and focused on the barriers, while the other palliative care service was open to change in practice. Once the benefits became apparent, the assessment was championed by the Clinical Nurse Consultant at that service. Due to the many and varied reasons for the reluctance by the health professionals to change practice, the employment of staff members committed to championing assessment may be what is required to effect change in future. Changing practice in healthcare is challenging due to entrenched working routines where opposition to change, arising from the varying values, beliefs, and power of the different organizational groups, is well documented (Hendy & Barlow, 2012; Lockett, Currie, Waring, Finn, & Martin, 2012).

#### **Underlying health professionals' attitudes and hidden barriers to change.**

Substantial barriers to bereavement risk assessment were identified by reference group and evaluation focus group members that may not be easily or quickly resolved. Such barriers included systems of care issues; for example, funding and staffing skillsets, patients moving between multiple services, late referral to palliative care, and contact with family caregivers (Sealey, O'Connor, Aoun, et al., 2015) as has been mentioned earlier. Some barriers, particularly those relating to gatekeeping where staff members allocate support services (Venes, 2005) based on intuition and observation, may stem from resistance to change and entrenched ways of working (Lockett et al., 2012). Further research should be directed to these aspects of clinical practice in order to understand and remedy these barriers to assessment.



The following explanatory models may partially explain the above findings.

***Defensive practice.*** Unwillingness to engage in caregiver assessment by the health professionals can be partially explained by defensive practice, which stems from fear of not being able to meet caregiver support needs (Mullen et al., 2008), as was voiced by the in-patient unit staff in this study. In engaging in defensive practice, self-protection against blame and possible litigation takes priority over that which serves the client's best interests. According to Mullen et al. (2008), emotionally charged situations are more likely to engender defensive practice where clinicians feel vulnerable in relation to accountability and engage in more observation than is clinically necessary. The authors suggest that nurses, in particular, feel vulnerable to the possibility of adverse events.

***Paternalistic model.*** In medicine value has traditionally been placed on clinicians' professional expertise and knowledge, and their capacity to interpret patient (and family caregivers') problems (Mullen et al., 2008). Such a paternalistic medical model of care tends to be disempowering, whereby patients and family caregivers put themselves in the hands of 'experts' who are qualified to know and provide what is 'best'. It is possible that health professionals who are experts prior to death, may be, with the best of intentions, disempowering caregivers by making assumptions about their grief (Brickman et al., 1982). Medical teams may be more likely to use a paternalistic model in an attempt to protect the family and patient from the burden of making difficult decisions under duress (Davidson et al., 2007). Davidson and colleagues suggest that in Europe and North America there has been a move toward a shared decision-making model that will be more culturally respectful of individual needs; however, such a model requires communication and family meeting facilitation skills.

Holding expert knowledge places clinicians in positions of power giving them certain licence to engage in their work autonomously (Waring & Currie, 2009). Such autonomy would be undermined by a shift in practice, enforced by organizational expectations where staff members would be required to conform. Waring and Currie (2009) suggest that professionals often oppose change and curb managerial authority by asserting their professional expertise and agency. The shift from clinicians'

professional judgement and expertise towards giving caregivers a voice may have been regarded as a challenge to the health professionals' jurisdiction.

***The medical model and discourse throughout the illness.*** It is possible that the predominance of paternalistic medical thinking throughout the active treatment phases of the patient's life-limiting illness, where patients and families are urged to 'fight' by well-meaning health professionals, may also contribute to family members' confusion in relation to communication, where they are still continuing the 'fight' even when death is imminent (The, Anne-Mei., Hak, Koëter, & van der Wal, 2000; Workman, 2009). Additionally, the recent trend towards later referral to palliative care (Zhang et al., 2006) and more aggressive treatment adds to peoples' perceptions that death might be avoided, thus leaving family members ill-prepared and confused by communications with health professionals as the death nears (Workman, 2009).

***Communication skills and knowledge of grief and loss processes.*** O'Connor and Fisher (2011) has shown that role boundaries of palliative care multidisciplinary team members are often blurred, which may lead to issues in who communicates with caregivers about bereavement. Powazki and colleagues (2014) found that nurses, particularly those who are younger and less experienced, believed that they had insufficient education in communication skills for end-of-life issues and, as a result, felt at a disadvantage professionally which affected them emotionally and personally. The lack of up-to-date knowledge may also be a factor in the reluctance by the in-patient unit staff to administer a self-report assessment (O'Connor & Breen, 2014; Powazki et al., 2014) and could be remedied by education.

***Organizational culture.*** As mentioned previously, it is becoming increasingly likely that palliative care service funding will be more directly linked than at present to compliance with various standards such as person-centred care (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2011; Victorian Government, 2014). It is possible that engagement in bereavement risk assessment to meet future funding requirements was imposed by management as a top-down strategy and was met with resistance in an attempt to retain professional autonomy in the present study. Clearly, research is crucial to establish evidence-based best practice (Duke & Bennett, 2010) and services should strive for such goals. Additionally, the identification of client safety and clinical risk has become a prime focus for health

services worldwide (Waring & Currie, 2009) and, if coupled with funding conditions, compliance with the provision of bereavement support standards will become mandatory.

While a person-centred care framework is an objective of health services, the ability to carry out the ideal is often shaped by the nature of staff workloads and organizational culture and, as such, change to practice is outside the remit of clinical staff. Moving more effectively towards the delivery of person-centred care (and thus shared decision-making with caregivers and patients) will require changes at an organizational level, particularly in relation to having appropriate skill mixes in staffing, and it will require ongoing commitment by individual health practitioners and service management (McCormack & McCance, 2006). The success of person centred care is also dependent on having staff with appropriate skills sets who work in an environment of mutual respect and trust; however, this is not always supported by the systems of care where budgets and work protocols are at odds with the ideal of care, and where the competing demands of a busy workplace lead to task-orientation rather than person-orientation (Ross et al., 2015).

The focus group evaluation in the present study highlighted concerns about increased workloads if a bereavement risk assessment procedure were to be implemented; however, Kirkley and colleagues (2011) suggest that health professionals need to move beyond claims of being short-staffed or too busy, given the many benefits to be gained from family centred care. Another concern raised during the evaluation at the in-patient unit related to a fear of “opening a can of worms” should a caregiver rate an item on the measure that might require a response from a staff-member. Bell (2013) states that such beliefs hinder rapport with families and limit conversations that might otherwise be beneficial. Rather, research shows that care focused on a person’s individual needs benefits not only the person receiving care and their family members, but also positively increases job satisfaction of staff (Ross et al., 2015).

This study has highlighted the many complex issues relating to the practical application of a bereavement risk assessment model. However, the study has also shown that many such obstacles can be overcome, particularly if there is support from a staff-member who champions the process of change and sees value in the new

practice. The Clinical Nurse Manager at the consultative team was open to change in the areas where she saw benefits in using a caregiver self-report measure.

### **The Role of the Champion in Healthcare as an Agent of Change**

Hendy and Barlow (2012) indicate that individuals can champion change by circumventing hierarchical groups within organizations. Such agents of change or ‘institutional entrepreneurs’ (Lockett et al., 2012) are those who have the vision to grasp alternative means of working that may have previously been stifled by the interests, opinions, and power of various organizational stakeholders or individuals. Champions generally step forward unexpectedly and informally and are enthusiastic in their support of the innovation, often taking on the role as a personal commitment (Hendy & Barlow, 2012). Champions are usually those who are most affected by problems with current practice and who are less entrenched in organizational norms; however, they frequently occupy job roles that make change difficult to achieve (Lockett et al., 2012).

The champion’s task is to facilitate change in practice by influencing and motivating other team members, drawing the team and management together by their enthusiasm for the innovation with a well-communicated vision (Hendy & Barlow, 2012). The present study has demonstrated the value of engaging key staff members to champion change, offering a means to the implementation of a bereavement risk assessment protocol when the time is right to do so.

### **The Role of Education in the Process of Change**

Evaluation at both in-patient and consultative services identified the need for staff education on grief and bereavement; how to conduct sensitive conversations around grief, bereavement, and emotive topics; how to deal with caregiver needs; and how to put referral processes in place. As such, an important finding of this study is the need for education to update and up-skill health professionals so that they may be equipped to assist family caregivers more effectively as they care for a significant other throughout life-limiting illness. While updating grief knowledge might primarily occur through palliative care professional development programs, it would also be fitting for tertiary educational organisations to review the content of their courses so

that they could better equip future health professionals in this regard (O'Connor & Breen, 2014).

In summary, key findings from the present study highlighted the numerous complexities to bereavement risk assessment, identified many barriers to the implementation of an assessment protocol, and also indicated what might facilitate moving towards improved practice in an assessment protocol. As such, the study has laid the groundwork for developing an assessment model.

### **Limitations of the Research**

The small sample size of caregivers who engaged in the pilot of the new measure as an assessment model, makes it impossible to generalize to the broader caregiving population. While the 19 caregivers who participated in the pilot indicated that the measure was acceptable to complete, it is unknown whether the majority of caregivers across various caregiving situations along the caregiving trajectory might also find it acceptable or helpful, and further research is needed. The study was also unable to determine whether or not an assessment protocol would identify those caregivers at risk of poor bereavement outcomes so that palliative care health professionals could provide a helpful or appropriate response. The lack of greater participant numbers and participation across different service models of care also made it difficult to determine the optimal timeframe to conduct the assessment between admission of the patient and separation from the service. It is possible optimal assessment timeframes will differ at each service type and also needs further probing. Due to lack of participation by all three service models of care, the study's findings were not able to demonstrate how a bereavement risk assessment model might be applied in different settings.

### **Directions for Future Research**

This study has found that caregiver bereavement risk assessment should be focused on the patient's pre-death interval, between the patient's admission to the service and death. Findings from the study also indicate that health professionals believe that within that interval there are periods where assessment should not be administered. Further research needs to be conducted to ascertain caregiver acceptability of completing an assessment measure, from between the patient's

admission to the service to the patient's death, to establish the best time to administer the assessment. Random sampling of caregivers should be used rather than staff selecting caregivers based on their perceived capacity to complete an assessment.

The many issues relating to assessment practice identified during this study need further examination so that by working around the barriers to assessment, the facilitators of change can be harnessed. Further research needs to be conducted in relation to organizational culture and clinical practice in terms of attitudes by staff members, such as defensive practice or paternalistic models of providing care so that barriers to assessment may be broken down more easily. Further research needs to be conducted in a variety of palliative care service models of care, as patient and family contact, length of patient stay, and service provision may influence ways in which a bereavement risk assessment protocol may be applied in clinical practice.

Findings from the present study indicate that the self-report assessment could be modified to become part of a staff-led conversational process for those caregivers considered unsuitable to engage in completing a measure. The measure was also considered to have potential to be incorporated into advanced health care directives and care of the dying pathways. As such, further research is needed to substantiate whether or not these proposed modified assessments would be applicable, clinically useful or feasible in practice.

As identified in the present study, education for health professionals on grief, loss, bereavement, conducting sensitive conversations, providing support and referral processes needs to be put in place as a matter of priority so that better outcomes can be achieved for caregivers. However, more research is needed to determine the best way to conduct such education, especially given the many barriers to change in practice as discussed above.

Triage pathways and referral processes should be set-up for palliative care services so that individual needs can be appropriately met; however, to do this, research needs to be conducted on how to best meet the needs of the various groups so that services can be put in place. It would seem the needs of the high-risk group, in accordance with a public health model (Aoun, Breen, et al., 2012), are being met through better mental health outcomes initiatives in Australia (Pirkis et al., 2011); however, for those in the medium-risk group, community-based support groups, and/or

volunteer-led support programs should be examined to establish their suitability for the needs of these individuals, and whether or not such support is effective in preventing these individuals from developing complex grief issues in time.

Given that Australia is a multicultural society and that culture is constantly changing, assessment will need to meet the needs of any individual's beliefs within the context of their cultural values (Kristjanson & Lobb, 2004). More research is needed in this area to determine how to meet varying cultural bereavement needs sensitively and appropriately, both in assessment and support, as well as how to integrate findings and education into clinical palliative care practice.

Little research has been conducted on prolonged or complicated grief that may originate prior to a death (Tomarken et al., 2008), therefore, focus needs to be directed towards the many caregivers who may have pre-existing undetected depression and/or anxiety, particularly given its association with stress and burden of care prior to the patient's death (Boerner & Schulz, 2009; Guldin et al., 2012; Hudson, Thomas, et al., 2011). Bonanno (2006) suggests that some who struggle with complicated grief responses following the death are responding to problems encountered prior to the loss; moreover, these individuals experience ongoing elevated symptoms long after those with complicated grief (arising from their loss alone) begin to improve. Given depressive disorders are prevalent in the community and caregiving burden increases this risk, these individuals should be identified so that appropriate and timely intervention can be put in place. However, comorbid depression or anxiety poses a problem for assessment due to reliance on retrospective accounts of symptoms (Bonanno, 2006) where there is a tendency for errors in recall in relation to, for example, the intensity of symptoms. As Bonanno suggests, long-term prospective studies are needed; however, such studies are costly, time-consuming and labour-intensive.

While substantial research has been conducted on bereavement and grief responses in recent years, still more is needed (Bonanno, 2006). As Rando (2013) states, it is unlikely that grief will be seen as a solitary concept given the complexity of grief responses. Guldin and colleagues (2013) suggest that a lack of unity in relation to symptoms and predictors of complicated grief contribute to the challenges experienced by health professionals in assessment. Until more is known about grief, grief responses

and ways of effectively supporting those with grief, assessment will likely remain inadequate, yet there is a pressing need to identify those at risk to prevent poor bereavement outcomes. As discussed earlier in this chapter, a separate term to describe the situation of those individuals at risk of complex or maladaptive responses to grief, triggered by the death of a significant other, is needed to avoid the confusion in relation to grief responses and grief diagnoses and requires further research.

Rando (2013) notes the present dearth of grief measures, and is critical of the reliance on assessing distress rather than the processes underlying grief. She suggests that, while there is a correlation between distress and complex grief, clinicians risk being misled by assessing distress rather than grief, given distress does not necessarily give rise to complicated grief. As noted by the reference group, grief can be heightened in many people around the anniversary of a death (Sealey, O'Connor, Aoun, et al., 2015); however, this does not necessarily indicate complicated or prolonged grief in need of intervention, showing that assessment is extremely complex. In spite the difficulty in identifying risk factors for complicated grief, van der Houwen and colleagues (2010) believe that the development of a screening questionnaire should be achievable. The measure developed as a part of the present study requires psychometric testing to validate its properties. Such intensive research will require large participant numbers to look at psychometric properties and establish validity and reliability.

## **Conclusion**

The present study sought to develop a bereavement risk assessment model for palliative care using existing grief measures; however, the lack of suitable measures (Sealey, Breen, et al., 2015) led to the development of a new brief, caregiver self-report grief measure based on risk factors for complicated grief (Lobb et al., 2010). A number of barriers to bereavement risk assessment affected how the model could be applied in clinical practice, and highlighted the complexity of issues affecting bereavement support in palliative care. The inability to pilot the measure on sufficient numbers of caregivers across a variety of service settings left questions remaining in regard to whether or not a brief self-report assessment might enhance present assessment and the allocation of support. However, it appears that some of the identified barriers could be overcome. Until valid and reliable bereavement risk



assessment can be achieved in palliative care, delivery of appropriate bereavement support will continue to be provided in an ad hoc fashion with those most in need of support likely to remain unsupported (Kristjanson & Lobb, 2004).

Action research methodology collaboration with palliative care stakeholders, (health professionals, caregivers and bereaved former caregivers), provided valuable information in relation to the barriers that hamper bereavement risk assessment, and the facilitators that need to be harnessed to influence change. This study is unique in the way it has mapped the issues in relation to assessment practice in Western Australian palliative care services and has therefore laid the groundwork for this essential work to progress in future.



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**From:** [Debbie Ashby](#)  
**To:** [Margaret Sealey](#)  
**Subject:** Re: ACTION REQUIRED: Palliative Medicine Contributor Form  
**Date:** Friday, 13 February 2015 6:04:53 PM

---

Dear Margaret

Thanks for your email. Providing your thesis is a non-commercial publication (I assume it will just be bound for your library/institution?) then the publishers are happy for you to include the paper in your thesis, but ask obviously that it is clearly noted that the article was originally published in Palliative Medicine with clear reference to volume, issue, DOI etc. I would imagine that by the time you are ready to submit your PhD thesis that version 3 will be available!

Hope this helps!  
Best wishes  
Debbie  
Editorial Manager  
Palliative Medicine

On 13 February 2015 at 05:50, Margaret Sealey

<[margaret.sealey@postgrad.curtin.edu.au](mailto:margaret.sealey@postgrad.curtin.edu.au)> wrote: Dear Ms

Ashby,

Thank you so much for your willingness to publish this manuscript.

I would just like to clarify one point before submitting this contributor form.

This work has been one part of my PhD project, and as such I would like to include this in my thesis, hopefully towards the end of this year.

My understanding is that I can use version 1 as I like, however, I would clearly need to reference the SAGE article, so perhaps Version 3 is best.

Using the article (Version 3), would also be permissible, again referencing & linking to the DOI?

If I understand correctly, I expect I may need written permission from you to do this to include with my thesis, and I am wondering if this would be possible to do please?

Kind regards, Margaret  
Sealey

-----Original Message-----

From: [onbehalfof+Debbie.Ashby+bristol.ac.uk@manuscriptcentral.com](mailto:onbehalfof+Debbie.Ashby+bristol.ac.uk@manuscriptcentral.com)

[mailto:[onbehalfof+Debbie.Ashby+bristol.ac.uk@manuscriptcentral.com](mailto:onbehalfof+Debbie.Ashby+bristol.ac.uk@manuscriptcentral.com)] On Behalf Of  
[Debbie.Ashby@bristol.ac.uk](mailto:Debbie.Ashby@bristol.ac.uk)

Sent: Wednesday, 11 February 2015 6:40 PM To:

Margaret Sealey

Subject: ACTION REQUIRED: Palliative Medicine Contributor Form 11-Feb-2015

Dear Ms. Margaret Sealey,

Your manuscript "A scoping review of bereavement risk assessment measures: Implications for palliative care." has been accepted for publication in Palliative

Medicine.

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If you have any questions please contact the Editorial Office. With best wishes,

Debbie Ashby

[Debbie.Ashby@bristol.ac.uk](mailto:Debbie.Ashby@bristol.ac.uk) Palliative

Medicine Editorial Office





**Title:** A scoping review of bereavement risk assessment measures: Implications for palliative care:  
**Author:** Margaret Sealey, Lauren J Breen, Moira O'Connor, Samar M Aoun  
**Publication:** Palliative Medicine  
**Publisher:** SAGE Publications  
**Date:** 07/01/2015  
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**Sent:** 05 November 2015 08:29  
**To:** BMCSeriesEditorial  
**Subject:** permission for publication in thesis

Dear Ms Ducot,  
I trust this finds you well.

In October this year you published an article that I had written for *BMC Palliative Care* and I am seeking your written permission to use this as part of my thesis. (Publication details in attached letter.)

It is a university requirement to have a signed statement from the publisher for inclusion in the appendices of the thesis.

I am attaching the letter and statement here and wonder if I can impose upon you to sign, scan and return via email so that I can meet these requirements please.




Thank you so much in anticipation.

Kindest regards,

Margaret Sealey

PhD Candidate | School of Psychology and Speech Pathology

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## **Appendix B**

### **Human Research Ethics Committee (HREC) approvals.**

As the lead HREC site, Royal Perth Hospital (EC2012/167) approval follows.

South Metropolitan Health Service (R/13/17) approved the study following Royal Perth Hospital, and .Curtin University approval (HR30/2013) was obtained following the first two approvals.





## HUMAN RESEARCH ETHICS COMMITTEE

Ref: EC 2012/167

30 January 2013

(This number must be quoted on all correspondence)

Ms Claire Doyle  
Palliative Care  
Royal Perth Hospital

Dear Claire

**EC 2012/167 Developing a bereavement care assessment model for palliative care: A WA action research study**

I am pleased to advise that the above study is **APPROVED**.

The following general conditions apply to all approvals by this Committee, and starting a trial or research project following the issue of ethics approval will be deemed to be an acceptance of them by all investigators:

1. The submission of an application for Ethics Committee approval will be deemed to indicate that the investigator and any sponsor recognises the Committee as a registered (with AHEC) Health Research Ethics Committee and that it complies in all respects with the National Statement on Ethical Conduct Research Involving Humans and all other national and international ethical requirements. **The Committee will not enter into further correspondence on this point.**
2. All income arising from the study must be lodged in a hospital special purposes account. Performance of a clinical trial for a sponsor is a service for tax purposes and all GST obligations must be met.
3. The investigator will report adverse events accompanied by a statement as to whether or not the trial should continue. The Committee reserves the right to not receive reports whose complexity or level of detail requires the expenditure of unreasonable time and effort. The Committee receives voluminous paperwork relating to adverse event reporting. From time to time the Committee chairman may require these reports to be summarised and approval is granted subject to the agreement of the investigator that he or she will prepare such a summary on request.
4. The Committee has decided that, as the responsibility for the conduct of trials lies with the investigator, all correspondence should be signed by the investigator.
5. All trial drugs must be dispensed by the Pharmacy Department. A fee is levied for this service and investigators must regard this fee as an item requiring a budget allocation. Alternatively, if a sponsor agrees, separate direct funding of pharmacy services may be undertaken. There are provisions for this fee to be waived for locally-inspired unfunded studies not having an external sponsor.
6. Though state institutions are outside the jurisdiction of the Privacy Act and related legislation, the Committee will assume that the privacy provisions of that Act will be the minimum standards applying during the conduct of a trial at Royal Perth Hospital. Traditional standards of patient confidentiality will apply.
7. The Committee will not acknowledge trial communications as a matter of course, unless they relate to a matter requiring Committee approval. Evidence of dispatch of a letter will be deemed to be evidence of receipt. This rule may be waived at the Committee's discretion on provision of a *pro forma* receipt by the investigator for the Chairman's signature and return. However, trivial correspondence (as judged by the Committee) will not be acknowledged even if a *pro forma* receipt is provided. Where an investigator requests written approval or written record of a matter for special purposes (say at the request of a sponsor), the investigator should prepare the required letter for the chairman's signature rather than expect the Committee secretary to prepare it. This mechanism increases the probability that the trial details in the letter are correct.
8. The Committee will provide the names and representative affiliation of members on request, but will not provide personal details or voting records.
9. A brief annual report on each project approved will be required at the end of each fiscal year, in default of which approval for the study may be suspended. Ethics approvals at RPH do not carry an expiry date so the annual report is an important part of Ethics Committee procedure.

---

The RPH Human Research Ethics Committee (HREC) is constituted and operates in accordance with NH&MRC Guidelines.

**Ethics Office** Level 5 Colonial House, Royal Perth Hospital, GPO Box X2213 Perth WA 6001  
Tel (08) 9224 2292 | Fax (08) 9224 3688 | Email [rph.hrec@health.wa.gov.au](mailto:rph.hrec@health.wa.gov.au)

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## **Appendix C**

Four participant information and consent forms (PICF) were required for participants throughout the phases of the project. These information and consent forms were required as follows:

1. Reference group stakeholder PICF
2. Advisory group stakeholder PICF.
3. Caregivers participating in pilot phase PICF.
4. Health professional participants in evaluation phase PICF.

The caregivers participating in the pilot phase PICF is included on the following pages as an example. This included final version was in response to the amendment to the study and was approved by Royal Perth Hospital as the lead site. The caregiver PICFs for the inpatient unit and the domiciliary community service had contact details relevant to each site. The remaining three PICFs for the reference group, advisory group and evaluation of health professionals were similar, but worded in accordance with the relevant phase of the study and contact information.



## **PARTICIPANT INFORMATION SHEET**

### **DEVELOPING A BEREAVEMENT RISK ASSESSMENT MODEL FOR PALLIATIVE CARE IN WA: AN ACTION RESEARCH STUDY**

You are being invited to participate in a multicentre research study, as part of a Doctor of Philosophy (Psychology) thesis presently being undertaken at Curtin University. We are asking you to participate in this study because you are presently caring for a patient of a palliative care service. To help you decide whether or not to take part in this research study, it is important that you understand the purpose of the study and the procedures you will be asked to undergo. Please read the following pages carefully, as they will provide you with information about the assessments involved, and also the potential benefits, discomforts and precautions of the study. Please ask questions about anything you don't understand, or would like to have more information about. Before deciding to take part in the study, you may want to talk it over with a relative, friend or health worker.

If you decide to take part in this study, you will be asked to sign the consent section in the last part of this letter. By signing the consent form you are telling us that you

- Have understood what you have read,
- Consent to take part in the research project,
- Consent to be involved in the research as described, and
- Consent to the use of your personal information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

#### **Nature and Purpose of the Study**

The aim of this study is to develop a bereavement care model for use in palliative care services. In order to provide appropriate bereavement support for carers, it is first necessary to develop a way to assess grief. This type of research is necessary so that palliative care services can better assess families and carer's bereavement support needs, so that appropriate bereavement support can be offered to carers such as yourself. Perth palliative care services are working together on this project from three different palliative care services.

#### **What the Study Will Involve**

If you decide to participate in this study, you will be asked to complete a short pencil and paper questionnaire, in relation to your thoughts and feelings about your present situation caring for a patient in a palliative care service. The questionnaire will take approximately 5 minutes to complete. It will be viewed by the palliative care staff in order to assess your bereavement support needs. The questionnaire will be retained by the research team so that responses may be analysed and scored, and mapped onto an assessment model for ongoing use in palliative care.

You will also be asked to fill in a brief feedback form, which will take approximately 10 minutes to complete, in order to evaluate how you found the assessment procedure. This is to find out if the assessment model is acceptable to people caring for a patient in a palliative care service, and to find ways that we might make the process a better experience.

There are no costs associated with participating in this research project, nor will you be paid. However, you may go in a draw to win one of three \$50 Myer vouchers. This will entail giving contact details so that you can be notified of the outcome.

### **Do I have to take part in this research project?**

Should you choose not to participate in this study, or should you participate and then decide to withdraw from the research, will not in any way interfere with, or prejudice, the care of the patient, yourself or other family members, now or in the future. Your participation in this study is entirely voluntary.

### **Possible benefits of taking part in the research**

A potential benefit of participating in this study is that we may more readily identify the need for additional support with your grief. However, it is also possible that there may be no direct benefit to you from your participation in this study. While there is no guarantee that you will benefit, the knowledge gained from your participation may help others in future.

### **Possible discomforts, risks and disadvantages to taking part in the research**

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it, and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the team can arrange for you to have counselling or other appropriate support. Support will be provided by qualified staff, free of charge. They will not be members of the research team.

### **What if I withdraw from the research project?**

You are free to withdraw from the study at any time without giving any reason. If you do decide to leave the research project, no further personal information will be collected from you. Personal information already obtained will need to be retained to ensure that the results of the research project can be measured properly and complies with the law. You should be aware that data collected up to the time you withdraw, will form part of the research results. If you do not want your data included, you must tell the researchers when you withdraw from the research project.

### **What happens when the research project ends?**

Following collection of information on the questionnaire, the data obtained will be analysed. Once the evaluation of the study has been completed, a short report of the findings from the study will be prepared. Any participants who would like to have feedback about the research may have a report mailed to them. This will require you to give your contact details.

### **What will happen to information about me?**

By signing the consent form, you consent to the palliative care team reviewing the grief questionnaire, and the research team collecting and using personal information about you for the research project. Any information obtained in connection with this study that can identify you will remain confidential.

The personal information that the research team collect and use will be a questionnaire. It will be stored in a locked metal filing cabinet at Curtin University. The questionnaire will be coded so you won't be identified. Information will be available to members of the team of researchers for the express purpose of performing the study. The data collected for this study may be used in future research. All of the collected information will be destroyed after 7 years.

Information obtained during the research however, may be subject to inspection to verify the procedures and data obtained. Inspections would only be carried out by relevant authorities and their authorised representatives, such as the WA Department of Health, Curtin University, or as required by law. By signing the consent form, you authorise access to this confidential information to the relevant research personnel and regulatory authorities noted above.

It is anticipated that the results of this research project will be published, and also presented at conferences. Any such publications that might arise from this research will not identify participants in any way.

In accordance with Australian privacy laws, you have the right to request access to the information about you that will have been collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document, should you wish to access your information.

### **Complaints**

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible so that you can be assisted with arranging appropriate treatment and support.

### **Who is organising and funding the research?**

This research is being conducted by Margaret Sealey to obtain a PhD degree from Curtin University. This research is being funded through a Curtin University Postgraduate Scholarship. It is not anticipated that the University, palliative care services, or any other organisation will benefit financially from this research project. No member of the research team will receive personal financial benefit from your involvement in this research project, and you will not benefit financially from your involvement in this research project.

### **Further information and who to contact**

The person you should contact will depend on the nature of your query. If you would like further information concerning the project, or you have any problems which may be related to your involvement with the project, you can contact the researcher, Margaret Sealey on 0408 104 544, Email [Margaret.Sealey@postgrad.curtin.edu.au](mailto:Margaret.Sealey@postgrad.curtin.edu.au) , or any of the following people;

- Dr Moira O'Connor, Supervisor, telephone 9266 3450 Email: [M.OConnor@curtin.edu.au](mailto:M.OConnor@curtin.edu.au)
- Dr Lauren Breen, Co-supervisor, telephone 9266 7943 Email: [Lauren.Breen@curtin.edu.au](mailto:Lauren.Breen@curtin.edu.au)
- Professor Samar Aoun, Co-supervisor, telephone 9266 9293 Email: [S.Aoun@curtin.edu.au](mailto:S.Aoun@curtin.edu.au)

For matters relating to research at the site at which you will be participating, the details of the Royal Perth Hospital complaints person is Claire Doyle, Clinical Nurse Consultant, Palliative Care team, telephone 92242957 Email: [Claire.Doyle@health.wa.gov.au](mailto:Claire.Doyle@health.wa.gov.au)

If you have any complaints about any aspect of the project, the way it is being conducted, or any questions about being a research participant in general, then you should contact Mr Mark Woodman, Ethics Coordinator, Royal Perth Hospital Human Research Ethics Committee on telephone 92243771, or Email [Mark.Woodman@health.wa.gov.au](mailto:Mark.Woodman@health.wa.gov.au) Alternatively, you may contact The Secretary, Human Research Ethics Committee, Office of Research and Development, Curtin University, PO Box U1987, Perth. WA 6845, or by telephone 92669223, or Email [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au)

Thank you for taking the time to read this information. If you have understood all of the information, and would like to participate in this study, please let a member of the staff know, and you will be contacted shortly about taking the next step – obtaining your written consent on the attached consent form, and arranging a convenient time and place for the short questionnaire assessment and feedback.

This study has been approved by Royal Perth Hospital's Human Research Ethics Committee (Approval EC2012/167), South Metropolitan Health Service Human Research Ethics Committee (Approval R/13/17), and Curtin University Human Research Ethics Committee (Approval HR30/2013). The study is being conducted in accordance with the National Statement on Ethical Conduct in Research Involving Humans (NHMRC). This statement has been developed to protect the interests of people who agree to participate in human research studies.

**CONSENT FORM**

**DEVELOPING A BEREAVEMENT RISK ASSESSMENT MODEL FOR PALLIATIVE CARE IN WA: AN  
ACTION RESEARCH STUDY**

**Protocol Number:** EC2012/167

**Coordinating Principle Investigator:** Claire Doyle

**Principle Investigator:** Margaret Sealey

**Location:** Royal Perth Hospital

**Declaration by participant:**

I have read the Participant Information Sheet, or someone has read it to me in a language I understand.

I understand the purpose, procedures and risks of the research described in this project.

I have had the opportunity to ask questions, and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described, and understand that I am free to withdraw at any time during the project, without affecting the care of the person I am caring for, myself or other family members now or in the future.

I understand that I will be given a signed copy of this document to keep.

Signature..... Date.....

**Declaration by Researcher:**

I have given a verbal explanation of the research project, its procedures and risks, and I believe that the participant has understood that explanation.

Name of Researcher (please print).....

Signature..... Date.....

Note: All parties signing the consent section must date their own signature.

Please indicate if you would like a copy of the research outcome at end of study. YES ☐ NO ☐

*If yes, please provide contact details.....*





## **Appendix D**

Pool of items of risk factors and predictors of complicated and  
prolonged grief for potential use in the new measure

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**Pool of caregiver items: Risk factors and predictors of complicated and prolonged grief**

Domain	Item	Reference
<b><i>Relational Interpersonal</i></b>		
Dependency on relationship with the deceased, attachment, separation anxiety	"How dependent were you on (the deceased) emotionally?"	[Bereavement Dependency Scale] (Johnson et al., 2006)
	"How dependent were you on (the deceased) in general?"	[Bereavement Dependency Scale] (Johnson et al., 2006).
	"How dependent were you on (the deceased) socially?"	[Bereavement Dependency Scale] (Johnson et al., 2006).
	"During his/her life.....was a major source of emotional support for me."	[TTBQ, Part III, item 2] (S.S. Rubin et al., 2009).
	"My relationship with ..... had much avoidance and distance."	[TTBQ, Part III, item 5] (S.S. Rubin et al., 2009).
	"Life without _____ is too hard to bear."	[TTBQ, Part II, item 13] (S.S. Rubin et al., 2009).
	"I long for what was, and what we had and shared in the past."	[MM-CGI, item 2] (Meuser & Marwit, 2001).
Family function and cohesion	"Our family usually deals with problems by talking things through."	
	"Our family usually has good problem solving capabilities and we resolve issues by working together as a team."	
Perceived support from family, friends, others	"I am able to talk and share my feelings with other people and to receive their help and support."	[TTBQ, Part IV, item 18] (S.S. Rubin et al., 2009).

Domain	Item	Reference
	"I can rely on my family to support me in my grief."	[Grief Evaluation Measure- experiences section, item 20] (J. R. Jordan et al., 2005).
	"Connections with others outside the family are a significant source of support for me."	[TTBQ, Part I, item 15] (S.S. Rubin et al., 2009).
	"After this person's death, I lost interest in my family, friends and outside activities."	[TRIG past behavior, item 3] (Faschingbauer, DeVaul, & Zisook, 1987).
<b>Cognitive</b>		
	"I don't know what's happening. I feel confused and unsure."	[MM-CGI, item 6](Meuser & Marwit, 2001).
	"I lay awake most nights worrying about what's happening and how I'll manage tomorrow."	[MM-CGI, item 33] (Meuser & Marwit, 2001)
Rumination	"I am preoccupied with thoughts about my relative and his/her illness."	[Anticipatory Grief Scale, item 4] (Theut, Jordan, Ross, & Deutsch, 1991).
	"I think about my loss so much it is hard for me to do the things I normally do."	[Loss Inventory, item 3] (Niemeier, Kennedy, McKinley, & Cifu, 2004).
	"I cannot make sense of the death of my loved one."	[Grief Evaluation Measure, experiences section, item 36] (J. R. Jordan et al., 2005).
Negative thinking/pessimism	"The death of my loved one has made my outlook on life much more negative."	[Grief Evaluation Measure, experiences section, item 53] (J. R. Jordan et al., 2005).
	"I spend a lot of time worrying about the bad things to come."	[MM-CGI, item 12] (Meuser & Marwit, 2001).

Domain	Item	Reference
Injustice	"You think, 'what am I doing to deserve this?'"	[Rumination Scale, item 5] (Treynor, Gonzalez, & Nolen-Hoeksema, 2003).
Negative views of self/self-blame	"I blame myself for my relative's illness."	[Anticipatory Grief Scale, item 9] (Theut et al., 1991).
Perceptions about the future	"When things are going badly I am helped by knowing they can't stay that way forever."	[Yale evaluation of suicidality (YES) scale, item 7] (Latham & Prigerson, 2004).
	"It's a life phase, and I know we'll get through it."	[MM-CGI, item 23] (Meuser & Marwit, 2001).
Thinking > avoidance behaviour	"I avoid things that remind me of ....."	[TTBQ, Part II, item 11] (S.S. Rubin et al., 2009).
	"I go out of my way to avoid reminders of the person who died."	[Inventory of Complicated Grief, item 12] (Prigerson, Maciejewski, et al., 1995).
Intrusive thoughts	"I am flooded by thoughts and feelings about the death of....."	[TTBQ, Part IV, item 14] (S.S. Rubin et al., 2009).
<b><i>Dispositional, resilience, coping</i></b>		
	"I believe I am unable to adjust or cope with my problems."	[Yale Evaluation of Suicidality (YES) scale, item 12] (Latham & Prigerson, 2004).
Optimism/resilience	"I believe and trust in my abilities to cope on my own with the tasks of life."	[TTBQ, Part I, item 19] (S.S. Rubin et al., 2009).
	"I have managed to overcome difficult events in my life."	[TTBQ, Part IV, item 19] (S.S. Rubin et al., 2009).
	"I have discovered new personal resources since my relative's illness was diagnosed."	[Anticipatory Grief Scale, item 5] (Theut et al., 1991).

Domain	Item	Reference
	"I believe that I will be able to be happy again someday."	[Grief Evaluation Measure, experiences section, item 30] (J. R. Jordan et al., 2005).
	"I'm managing pretty well overall."	[MM-CGI, item 45] (Meuser & Marwit, 2001).
Trait dependency	"I miss so many of the activities we used to share."	[MM-CGI, item 2] (Meuser & Marwit, 2001).
<b><i>Spiritual/religious, worldview and meaning</i></b>		
Spiritual belief/Faith	"My values and beliefs are a significant source of support for me."	[TTBQ, Part I, item 18] (S.S. Rubin et al., 2009).
	"The death of my loved one has strengthened my faith in God."	[Grief Evaluation Measure, experiences section, item 22] (J. R. Jordan et al., 2005).
	"My spiritual life has been diminished by the death of my loved one."	[Grief Evaluation Measure, experiences section, item 52] (J. R. Jordan et al., 2005).
Making sense/meaning	"I feel that life is empty or meaningless without _____."	[Inventory of Traumatic Grief, item 14] (Boelen, van den Bout, de Keijser, & Hoijtink, 2003).
	"I'm at peace with myself and my situation in life."	[MM-CGI, item 22] (Meuser & Marwit, 2001).
<b><i>Mental health</i></b>		
	"Now I understand people who think about putting an end to their own life after losing a close person."	[TTBQ, part II, item 17] (S.S. Rubin et al., 2009).
	"Feel like you just could not make it through another day."	[Grief Experiences Questionnaire, item 8] (Bailley, Dunham, & Kral, 2000).

Domain	Item	Reference
	"Think of ending your own life."	[Grief Experiences Questionnaire, item 49] (Bailey et al., 2000).
Panic/anxiety	"I have felt a racing heart, sweaty, faint, trouble breathing, faint, or shaky when separated."	[Severity measure for separation anxiety disorder – Adult, item 4] (Craske et al., 2013).
	"I feel anxious and scared."	[MM-CGI, item10] (Meuser & Marwit, 2001).
Substance use	"I have needed help to cope with separation (e.g. alcohol or medications, superstitious objects)."	[Severity measure for separation anxiety disorder – Adult, item 10] (Craske et al., 2013).
Sleep disturbance/insomnia	"I'm having trouble sleeping."	[MM-CGI, item 21] (Meuser & Marwit, 2001).
<b><i>Environmental, situational, instrumental</i></b>		
Caregiver burden	I've had to make some drastic changes in my life as a result of becoming a caregiver."	[MM-CGI, item 40] (Meuser & Marwit, 2001).
	"My physical health has declined from the stress of being a caregiver."	[MM-CGI, item 4] (Meuser & Marwit, 2001).
	"I have felt tense muscles, felt 'on edge' or restless, or had trouble relaxing or trouble sleeping when separated."	[Severity measure for separation anxiety disorder – Adult, item 5] (Craske et al., 2013).
Circumstances during the episode of care and end-of-life	"I have difficulty controlling the disturbing images in my mind of my loved one at the time of his/her death."	[Grief Evaluation Measure, experiences section, item 38] (J. R. Jordan et al., 2005).
Stressful life events/financial resources	"The death of my loved one has created financial problems for me."	[Grief Evaluation Measure, experiences section, item 15] (J. R. Jordan et al., 2005).

Domain	Item	Reference
	"I've lost other people close to me before, but the losses I am experiencing now are much more troubling."	[MM-CGI, item 38] (Meuser & Marwit, 2001).
Preparedness for the death	"I am unable to accept the death of the person who died."	[TRIG present emotional feelings, item 12] (Faschingbauer et al., 1987).
	"The loss happened suddenly and unexpectedly."	[TTBQ, Part IV, item 2] (S.S. Rubin et al., 2009).
Perceived instrumental support	"I get excellent support from members of my family."	[MM-CGI, item 47] (Meuser & Marwit, 2001).

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## **Appendix E**

A comparison of the four drafts of the measure during step three of developing the measure in collaboration with the advisory group.



#	Draft	Item content	Domain/risk factor
1	Orig A B C D	<p>"The loss happened suddenly and unexpectedly" (TTBQ, Part IV, item 2)</p> <p>Arriving at this stage of the illness happened suddenly and unexpectedly.</p> <p>Arriving at this stage of the illness happened suddenly and unexpectedly <b>for me.</b></p> <p>1 Arriving at this stage of the illness happened suddenly and unexpectedly <b>for me.</b></p> <p><b>1 I think that arriving at this stage of the illness has happened so suddenly, that I'm not ready.</b></p>	Preparedness for death
2	Orig A B C D	<p>"How dependant were you on (the deceased) emotionally? (Bereavement dependency Scale)</p> <p>"During his/her life, _____ was a major source of emotional support for me" (TTBQ, Part III, item 2)</p> <p>..... has been a major source of emotional support for me.</p> <p><b>3</b> I usually turn to .....in times of need, and I always talk things over with him/her. I don't know how I'll manage without that support." (this became item 3.)</p> <p><b>6</b> I usually turn to .....in times of need, and I always talk things over with him/her.</p> <p><b>6 I turn to ..... in times of need.</b></p>	Attachment/dependence
3	Orig A B C D	<p>"How dependent were you on (the deceased) for household management?" (Bereavement Dependency Scale)</p> <p>How dependent are you on ..... in general?</p> <p>2 How dependent/reliant are you on .....in a practical sense? (moved to item 2)</p> <p><b>5</b> I am reliant on .....<b>for assistance and support with the activities of daily living.</b></p> <p><b>5 I am reliant on .....for assistance and support every day.</b></p>	Dependence/support needs
4	Orig A B C D	<p>"Life without _____ is too hard to bear" (TTBQ, Part II, item 13)</p> <p>The thought of life without .....is too hard to bear.</p> <p>The thought of life without .....is too <b>challenging.</b></p> <p><b>7</b> The thought of life without .....is too <b>difficult to contemplate.</b></p> <p><b>7 I am fearful of how life without ..... will be.</b></p>	Attachment
5	Orig A B C	<p>"I'm at peace with myself and my situation in life." (MM-CGI, item 22)</p> <p>I feel at peace with myself and what's happening.</p> <p>I feel at peace with myself and what's happening.</p> <p><b>REMOVED</b></p>	Adaptive coping
6	Orig A B C D	<p>"I've lost other people close to me, but the losses I am experiencing now are much more troubling." (MM-CGI Item 38)</p> <p>I've lost other people close to me before, but the loss I am experiencing now is much more troubling.</p> <p>I've lost other people close to me before, but the loss I am experiencing now is much worse.</p> <p><b>8</b> When thinking about what's happening, it now feels like the worst experience I've ever had.</p> <p><b>8 I believe what's happening now is the worst experience I've ever had.</b></p>	Previous losses

7	Orig A B C D	<p>"I feel very guilty about the death of my loved one." (GEM Experiences Section, Item 11)</p> <p>"When I think of _____, I feel strong guilt and regret that I didn't do things differently." (TTBQ, Part II, item 8)</p> <p>I feel guilty about .....’s illness and feel I should have done things differently from diagnosis.</p> <p>I think about .....’s illness and feel I should have done things differently from diagnosis.</p> <p><b>11</b> I feel guilty about .....’s illness, and thinking back to around the diagnosis I wish I’d done things differently.</p> <p><b>12 I feel guilty about the past choices we made in relation to this illness.</b></p>	Rumination/pessimism
8	Orig A B C D	<p>"I have distracted myself to avoid thinking about being separated." (Severity measure for separation anxiety disorder – adult, Item 9)</p> <p>I distract myself to avoid thinking about what’s happening.</p> <p>I distract myself to avoid thinking about what’s happening.</p> <p><b>3</b> I <b>must</b> distract myself to avoid thinking about what’s happening.</p> <p><b>3 I avoid thinking about what is happening.</b></p>	Cognitive function/avoidance
9	Orig A B C D	<p>"I don't know what is happening. I feel confused and unsure." (MM-CGI, Item 6)</p> <p>I don't know what's happening. I feel confused and unsure.</p> <p>I don't know what's happening. I feel confused and unsure.</p> <p><b>2</b> I don't know what's happening. I am concerned that my thinking is confused and unsure.</p> <p><b>2 I'm confused and unsure about what's happening.</b></p>	Cognitive function
10	Orig A B C D	<p>"I lie awake most nights worrying about what's happening and how I'll manage tomorrow"( MM-CGI, Item 33)</p> <p>I lie awake at nights worrying about what's happening and how I'll manage tomorrow.</p> <p>I lie awake at nights worrying about what's happening and how I'll manage tomorrow.</p> <p><b>10</b> I lie awake at nights worrying about what's happening and how I'll manage in the future.</p> <p><b>11 I worry about what's happening.</b></p>	Rumination/ worry/ anxiety
11	Orig A B C D	<p>"I have needed help to cope with separation (e.g. alcohol or medications, superstitious objects)" (Severity measure for separation anxiety disorder – adult, Item 10)</p> <p>At present, I have trouble getting through a 24 hour period without having alcohol or drugs to help me.</p> <p>At present, I need alcohol and/or drugs to help me cope.</p> <p><b>13</b> I need alcohol or drugs to help me cope.</p> <p><b>REMOVED</b> (by academic team)</p>	Substance use/maladaptive coping
12	Orig A B C	<p>"The death of my loved one has made my outlook on life much more negative." (GEM Experiences Section, Item 53)</p> <p>This illness has made my outlook on life much more negative.</p> <p>This illness has made my outlook on life much more negative.</p> <p><b>REMOVED</b></p>	Pessimistic thinking

13	Orig A B C D	<p>“My values and beliefs are a significant source of support for me” (TTBQ Part 1, item 18)</p> <p>My values and beliefs are a significant source of support for me.</p> <p>My values and beliefs are a significant source of support for me.</p> <p><b>4 I have a belief system</b> that is a source of support and helps me cope.</p> <p><b>4 My spiritual beliefs are a source of support for me.</b></p>	Meaning /spirituality/religion
14	Orig A B C	<p>“I believe I am unable to adjust or cope with my problems.” (Yale Evaluation of Suicidality (YES) Scale, item 12)</p> <p>I believe I am unable to adjust to my situation, or cope with my problems.</p> <p>I am unable to adjust to my situation or cope with my problems.</p> <p><b>REMOVED</b></p>	Cognitive/rumination
15	Orig A B C D	<p>“I have felt a racing heart, sweaty, trouble breathing, faint, or shaky when separated” (Severity measure for separation anxiety disorder- adult, Item 4)</p> <p>My heart feels like it’s racing. I feel sweaty, faint, shaky and have trouble breathing.</p> <p>My heart feels like it’s racing. I feel sweaty, faint, shaky and have trouble breathing.</p> <p>I feel anxious and panicky.</p> <p><b>14</b> At times I feel anxious and panicky and experience physical sensations (for example rapid breathing, faint, shaky, sweaty)</p> <p><b>14 I feel anxious and panicky.</b></p>	Emotional distress
16	Orig A B C D	<p>“Now I understand people who think about putting an end to their own life after losing a close person” (TTBQ Part II, item 17)</p> <p>Now I understand why people think about ending their own life when they have lost someone close to them.</p> <p>Now I understand why people think about ending their own life when they have lost someone close to them.</p> <p><b>16</b> I have thoughts of ending my own life.</p> <p><b>16 I have thoughts of ending my own life.</b></p>	Suicidal ideation
17	Orig A B C	<p>“I am unable to accept the death of the person who died” (TRIG present emotional feelings, item 12)</p> <p>I cannot accept what’s happening.</p> <p>I cannot accept what’s happening.</p> <p><b>REMOVED</b></p>	Preparedness for death
18	Orig A B C D	<p>“I’m managing pretty well overall” (MM-CGI, Item 45)</p> <p>I’m managing pretty well overall.</p> <p>I’m managing pretty well overall OR I’m finding I can cope okay.</p> <p><b>17</b> Overall, I am finding that I am managing better than I thought I could.</p> <p><b>17 I believe I am managing better than I thought I could on the whole.</b></p>	Resilience/coping
19	Orig	“Connections with others outside the family are a significant source of support for me” (TTBQ, Part I, item 15)	Perceived support

	A	I feel like I have good support from family and friends at present.	
	B	I feel like I have good support from family and friends at present.	
	C	<b>20</b> I have good support from family and friends at present.	
	D	<b>20 I have good support from family and friends.</b>	
20	Orig	“My physical health has declined from the stress of being a caregiver” (MM-CGI, Item 4)	Caregiver burden
	A	My physical health has declined from the stress of being a carer.	
	B	My physical health has declined from the stress of being a carer.	
	C	My physical health has suffered as a result of being a carer.	
	D	<b>18 My health is suffering as a result of being a carer.</b>	
		<b><i>Draft C: Items added following removal from draft B</i></b>	
9	C	Since the diagnosis, I’ve learnt to appreciate what’s important in life.	Resilience/adaptive coping
	D	<b>10 Since .....’s diagnosis, I appreciate what’s important.</b>	
12	C	I have been diagnosed with anxiety depression or other mental health conditions.	Comorbid/previous mental health diagnosis
	D	<b>REMOVED</b> (by academic team)	
15	C	Life seems quite meaningless and hopeless	Cognitive/meaning
	D	<b>15 Life seems meaningless and hopeless</b>	
19	C	I usually manage to overcome difficult events in my life.	Resilience/adaptive coping
	D	<b>19 I manage to overcome difficult events in my life.</b>	
		<b><i>Draft D: Items added following removal from draft C</i></b>	
9	D	<b>9 I can’t stop thinking about .....’s impending death.</b>	Intrusive thoughts/rumination
13	D	<b>13 I can’t help thinking about how unfair .....’s terminal illness is.</b>	Rumination

Two qualitative open sections with room to respond were added at the end of the self-report scale:

Can you think of anything that may affect your ability to care for yourself, and/or any other people you have responsibility for over the coming weeks? If so, please describe.

Was there anything identified in the questionnaire that needs to be addressed now? If yes, please say what that is.



**Sample A:** This first sample A measure was discussed with the bereaved former caregivers (C1 and C2) to assess acceptability of the questions before taking to the clinicians.

**Item 1:** “this stage of the illness happened suddenly and unexpectedly “ Both bereaved former caregivers elaborated on the first item, as both cared for patients over periods of months and years. They explained that while end-of-life hadn’t arrived particularly suddenly, given their loved ones had cancer and motor neurone disease respectively, for them it did seem sudden and they felt unprepared and believed it was a good question to ask. They both recounted feeling that their grief was invalidated when other people seem to perceive a palliative care death is easier because they’ve had time to prepare and commence grieving, and that this item validated their experience. For this reason “for me” was attached to the end of item one on the next draft (Sample B).

**Items 2 & 3:** Items regarding attachment and dependency were misunderstood by both caregivers, with both spending some time talking and thinking through what was being asked. Both thought they were important questions to ask, but the confusion regarding wording and concepts needs to be addressed.

**Item 2:** “.....has been a major source of emotional support for me.” As C1 said, *“I don’t expect my daughter to emotionally support me, but I would be devastated if something happened to her.”* While she could understand what the question was getting at, she believed it wasn’t clearly articulating what was being asked.

**Item 3:** “how dependant are you on ..... in general?” was also confusing. C2 thought it was asking who she depended on during the care of her husband. Both caregivers sought clarity on the word dependant; whether it was meaning dependant or reliant, whether in a practical sense, such as driving or for income, or in any other sense. Both caregivers pointed out that many palliative care patients are possibly unable to provide practical support to the caregiver for lengthy periods before their deaths, and as such the question is confusing.

**Item 4:** “the thought of life without... is too hard to bear.” C1 said she *“just wouldn’t have been able to go there”* with this question in the lead up to her husband’s death. C2 said that she wouldn’t have been able to answer that question back then (three and a half years ago). When asked whether the question should be asked or was it irrelevant, she said caregivers may answer differently at any time depending how they were feeling. She said people may feel relief that their care burden will be over, but then may feel guilty for thinking that, and that may be followed by depression and sadness.

**Item 5:** “I feel at peace”. C1 reacted quite strongly saying, *“no one would be at peace surely.”* C2 said it was *“a nice way of asking about acceptance”* and suggested that could mean different things to different people.

**Item 6:** “I’ve lost other people close to me” Both caregiver’s were okay with this item, with C1 suggesting substituting the word “worse” for “troubling” to make more sense.

**Item 7:** “I feel guilty about .....’s illness and feel I should have done things differently from diagnosis.” C2 thought this question would be likely to “*open stuff up*” but then said “*some people are more guarded than others*”, but perhaps this “*was the point of doing the assessment*”, in which case it should be asked. C1 didn’t see a problem in asking that question.

**Item 8:** “I distract myself to avoid thinking about what’s happening.” C1 had nothing to add, however, C2 said “*I actually love that [question]...this can actually be extremely healthy I believe. Denial is a wonderful thing when you’re under so much stress. If they said they were distracting all the time, then that’s not healthy. It’s such a good question.*”

**Item 9:** “I don’t know what’s happening. I feel confused and unsure.” Both caregivers thought it was a good question.

**Item 10:** “I lie awake at nights worrying...” Both caregivers thought it was a good question.

**Item 11:** “At present, I have trouble getting through a 24 hour period without having alcohol or drugs to help me” Both caregivers thought it was a reasonable question , however, C2 wondered if “*you’d get an honest answer...but they [caregivers] might go away and think about it, and think ‘perhaps I should do something about that.’*”

**Item 12:** “This illness has made my outlook on life much more negative.” C2 thought this through and asked if it would be better framed as “more positive” than “negative”, stating that looking back now those last precious weeks and months were positive sharing time together in spite of the illness.

**Item 13:** “My values and beliefs are a significant source of support for me.” Both caregivers thought that made sense and was a good question to ask.

**Item 14:** “I believe I am unable to adjust to my situation, or cope with my problems right now.” Both caregivers thought that made sense and was a good question to ask.

**Item 15:** “My heart feels like it’s racing. I feel sweaty, faint, shaky and have trouble breathing.” Both caregivers thought that made sense and was a good question to ask, particularly as to the “*impact on health*”, although the reasoning behind the item was to elicit somatic and panic responses.

**Item 16:** “Now I understand why people think about ending their own life when they have lost someone close to them.” C2 thought it was “*an important question*” and couldn’t think of another way to ask it. When asked whether she believed talking about it might put the idea into someone’s head (as had

been suggested by a clinical nurse and physician) she responded *"I actually feel reassured. I would feel glad that someone actually recognizes the consequences. I'm not alone here. Someone has thought 'it's a common feeling. I'm not a freak.'"* She believed if someone had made that decision [to suicide] *"...they're private about it. No one will give you the idea because you've already made that decision."* She believed it was better to ask and added *"perhaps as they read it [on the assessment measure], they might acknowledge to themselves, and they might seek help."*

**Item 17:** "I cannot accept what's happening." Both caregivers thought that made sense and was a good question to ask.

**Item 18:** "I'm managing pretty well overall." Both caregivers thought that made sense and was a good question to ask.

**Item 19:** "I feel like I have good support from family and friends at present". Both caregivers thought that made sense and was a good question to ask.

**Item 20:** "My physical health has declined from the stress of being a carer." Both caregivers thought that made sense and was a good question to ask.

Regarding responses true, mostly true, C2 said that it was *"a gentle way of asking. You can't be more specific than that."* However, she also thought some of the time, or all of the time might *"be less ambiguous and get a more honest response."*

Overall how did they feel about filling out the form: C1 thought she would have felt that she mattered and cared for if she had been asked to fill it out during care for her husband. C2 thought back and said she may not have wanted to fill it out at that time, but believed she would have been able to tell staff *"to hop on your bike"* if they had asked her to fill it out. However, on reflection she believes caregivers need to be given a voice and that something like this gives them a voice. *"If it had been given to me, as a thing I did periodically, I would be familiar with it."*

Were there any items they thought had been left off? C1 thought questions relating to financial concerns or feelings about anger or bitterness could be added. C2 believed that it would be preferable not to have any more items than the present 20 items on one page.

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**Sample B:** Very little was changed on Sample B, where it was taken to two clinicians (P1 and P2 - both Counselling Psychologists with palliative care experience) in the first clinician interview, and P3 (also a Counselling Psychologist with palliative care experience) in the second clinician interview.

**Item 1:** "Arriving at this stage of the illness this stage of the illness happened suddenly and unexpectedly for me." P1 and P2. *"Good question"*. P3 said about item 1 *"I had to read it about 3 or 4 times. I find the sentence a little bit obtuse. I couldn't understand what's actually meant. I don't know how to fix it. But apart from that it's a really good question because it identifies levels of comprehension, levels of denial, levels of defense mechanisms against*

*knowledge of impending death, but I find the sentence very difficult*" This was due to the English structure. Something that *'conveys a sense of shock'* would be preferable. *"The underlying thing that you're wanting to ask is really very relevant."*

**Items 2 and 3:** given the confusion experienced by the caregivers, items 2 and 3 were swapped, so that item 3 (how dependant are you on ...) in a general practical sense may be easier to introduce the idea of emotional and practical dependence. Psychologist 1 (P1) asked how I would see the questions two and three being different to a lay person, because she was also finding the meaning confusing. However after discussion, they agreed that they were two separate constructs. P3 stated *"I don't know how you can tease it out, but there's a difference between reliant and dependant, and practically and emotionally dependant. I think it's a very relevant question that certainly can identify risk factors definitely. It's difficult because you don't want to make it too elaborate either."*

**Item 2:** "how dependant are you on ..... in general?" P1 suggested changing dependant to reliant and stating "how reliant are you on .....?" may be more likely to elicit a response. Again, similar to what the bereaved former caregivers had said, the patient might not have been helpful by doing chores, but simply helpful by their presence to talk things over with.

**Item 3:** ".....has been a major source of emotional support for me." P1 suggested substituting emotional for psychological, so it encompasses "mental, emotions and feelings". Similar to C1, she could see differences in having emotional support, and not expecting emotional support from the patient but having intense feelings in relation to the patient.

**Item 4:** "the thought of life without... is too hard to bear" P2 suggested that it would be simply stating fact for most people. P1 asked if this was eliciting suicidal ideation, in which case it was of value. (It was pointed out that item 16 was specifically targeting suicidal ideation.) P2 commented that this may be asking the same question as Item 3 (the patient as a source of emotional support), and that it was a good question in relation to attachment, which they both believed was a strong indicator of complicated grief. P3 suggested 'too challenging' rather than 'too hard to bear', but suggested while it's a good question, it may not generate clinical data because that's 'normal grief' – *"it won't separate out the complicated grief as hoped"*.

**Item 5:** "I feel at peace with myself and what's happening." P1 suggested substituting "I feel at peace with myself" for "I accept what's happening." P2 said that was a good word because *"accepting doesn't mean liking."* P3 said this was *"a difficult question."* It could be possible someone saying that they are at peace may not be in touch with their emotions and would be difficult to assess without extensive background information. Rarely someone might be at peace because they've already made a decision to suicide following the death of their loved one. Doesn't really provide clinically useful information.

**Item 6 :** "I've lost other people close to me before, but the loss I am experiencing now is much worse." P2 stated, *"I actually quite like question 6. I think it is a very clever question because it sheds light on other significant losses."* P1 stated *"one of the situations I came across in the hospice many times was the*

*death of an adult child – huge risk factor.” P1 suggested perhaps the first part of the item doesn’t need to be stated and word it as “the loss I am experiencing now is much more troubling.” P2 said that as previous losses were important predictors of CG, then that needed to be screened, particularly as they encounter many clients who “can lose two or three people.” P2 said she had worked with clients whose spouses were dying, however the loss of their child previously was much more devastating for them. Both suggested this would be a better yes/no on a checklist item (with previous or comorbid mental health diagnoses, drug/alcohol use). P3 “that’s a really good question” However, P3 believes that one loss may not be more troubling than another, but if there have been past losses with other risk factors “there’s really cause for concern.” Like P1 & P2 she suggested this would be better on a yes/no checklist. She said that people will often talk about the patient’s illness or death, but afterwards they say that they forgot to mention that there’s been the death of a significant other when they were children. For some people who haven’t dealt with the earlier loss “it kind of goes into that part of their minds where they are not in touch with their main feelings about that, and if they have a small loss today, then all the old deaths can come tumbling in.”*

**Item 7:** “I think about .....’s illness and feel I should have done things differently from diagnosis.” P1 did not like the previous use of “I feel guilty” because it’s a thought not a feeling, and “I think” I should have done things differently, rather than “feel”. P2 stated in her experience “people just eat themselves alive thinking those sorts of thoughts.”

**Item 8:** “I must distract myself to avoid thinking about what’s happening. P2 stated this is a normal response. P1 said the addition of ‘must’ was more meaningful.

**Item 9:** “I don’t know what’s happening. I feel confused and unsure.” P2 stated this also comes up a lot and would be expected responses. P1 suggested removing “feel” because thinking is not feeling and stating instead “I am confused and unsure.”

**Item 10:** “I lie awake at nights worrying about what’s happening and how I’ll manage tomorrow.” P1 “that taps into depression” P2 “and anxiety as well”

**Item 11:** “At present, I have trouble getting through a 24 hour period without having alcohol or drugs to help me.” P1 suggested shortening it to “ At present I need alcohol/drugs to help me cope.” “It’s quite a long sentence and it’s I think a bit tippy toeing around it.”

**Item 12:** “This illness has made my outlook on life much more negative.” P1 suggested changing to “ my future is meaningless” or “....’s illness has made me feel hopeless about the future.”

**Item 13:** “My values and beliefs are a significant source of support for me.” There was some discussion on this and both agreed that in their experience religious/spiritual beliefs helped people cope better, and as such it was worth retaining, perhaps rewording to “my values and beliefs help me cope.”

**Item 14:** “I believe I am unable to adjust to my situation, or cope with my problems.” P1 *“is the question about adjusting in future or coping at present?”* suggested changing to a more direct statement “I am unable to cope with my problems right now.” She said *“what happens in the moment and how we deal with stress in the here and now, could be a predictor of how we deal with it in the future.”*

**Item 15:** “My heart feels like it’s racing. I feel sweaty, faint, shaky and have trouble breathing.” P1 “well that’s anxiety so ‘I often feel panicky’ and you can just put in some of the symptoms. ‘I feel anxious and panicky’.

**Item 16:** “Now I understand why people think about ending their own life when they have lost someone close to them.” P1 suggested this was not particularly reflective of suicidal ideation. *“I’d be asking directly you know if I’m having thoughts or plans or...”* P2 suggested adding “after my loved one dies” - *“that comes up a bit.”* She added that the PC services *“don’t like those type of questions.”* P1 said *“it’s a fallacy that if you tell people about the death of whatever that will make a person want to die if you talk about it with them. It’s not the same as copycat stuff.”*

**Item 17:** “I cannot accept what’s happening.” P1 stated *“that’s another acceptance question.”* P2 said “you could probably take that one out.”

**Item 18:** “I’m managing pretty well overall”. P2 said *“I actually quite like that question.”* P1 said *“I don’t know. It just doesn’t sit well. I would most probably like to hear something like ‘I’m finding I’m able to cope’ or something like that.”* P2 said that *“able to cope is a dicey question, because it brings up stuff for people the thought of not being able to cope. Most people are coping somehow.”* P1 thought that if people could say they were coping, they would be *“feeling quite positive about themselves.”* P2 still challenged the notion of coping saying *“but what is coping? Some people think drinking 2 bottles of wine per night is coping.”*

**Item 19:** “I feel like I have good support from family and friends at present”. P1 said to remove ‘feel’ and ‘at present’ and simply say “I have good support from family and friends.”

**Item 20:** “My physical health has declined from the stress of being a carer. Both thought it was a good question given *“many people get burnt out and tired.”* P3 *“Excellent question”*

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**Sample C:** Sample C was reviewed by three more grief counsellors who suggested further adjustment to items relating to attachment and dependency.

**Items 5, 12, 14, and 17** were removed in draft C.

**Item 2:** *“I usually turn to .....in times of need, and I always talk things over with him/her.” The second part, “I don’t know how I’ll manage without that support” was removed as it was considered to divide attention to two different questions. This item became Item 3 on Draft C.*

General comments:

- “You don’t want to ask unnecessary questions, because you want to keep it as brief as possible as well.” ( P1)
- “Who would fill the form out? The caregivers themselves or the staff?” (P1) > “There would need to be an explanation of why they were being required to fill it out, and it would need to be voluntary.”
- “It would be helpful if there was room for them to say more, and to stipulate if they would like to speak to somebody (e.g. Social worker or chaplain).” (P1).





## **Appendix F**

Grief and bereavement assessment (GABA) measure.



## *Grief and Bereavement Assessment - Palliative Care*

For each item, please circle the number that best describes you, or how you are thinking or feeling at present. Wherever a line like this ..... appears, please answer the statement as if the name of the person you are caring for is written on the line.

		Never	Rarely	Sometimes	Often	Always
1	I think that arriving at this stage of the illness has happened so suddenly, that I'm not ready.	1	2	3	4	5
2	I'm confused and unsure about what's happening.	1	2	3	4	5
3	I avoid thinking about what is happening.	1	2	3	4	5
4	My spiritual beliefs are a source of support for me.	1	2	3	4	5
5	I am reliant on ..... for assistance and support every day.	1	2	3	4	5
6	I turn to ..... in times of need.	1	2	3	4	5
7	I am fearful of how life without ..... will be.	1	2	3	4	5
8	I believe what's happening now is the worst experience I've ever had.	1	2	3	4	5
9	I can't stop thinking about .....s impending death.	1	2	3	4	5
10	Since.....s diagnosis, I appreciate what's important.	1	2	3	4	5
11	I worry about what's happening.	1	2	3	4	5
12	I feel guilty about past choices we made in relation to this illness.	1	2	3	4	5
13	I can't help thinking about how unfair .....s terminal illness is.	1	2	3	4	5
14	I feel anxious and panicky.	1	2	3	4	5
15	Life seems meaningless and hopeless.	1	2	3	4	5
16	I have thoughts of ending my own life.	1	2	3	4	5
17	I believe I am managing better than I thought I could on the whole.	1	2	3	4	5
18	My health is suffering as a result of being a carer.	1	2	3	4	5
19	I manage to overcome difficult events in my life.	1	2	3	4	5
20	I have good support from family & friends.	1	2	3	4	5

Can you think of anything that may affect your ability to care for yourself, and/or any other people you have responsibility for over the coming weeks?

If so, please describe:

.....

.....

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Was there anything identified in the questionnaire that needs to be addressed now? If yes, please say what that is

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## **Appendix G**

Caregiver feedback form – pilot phase.





## Feedback Form

### Grief and Bereavement Assessment – Palliative Care

I would like to invite you to complete a feedback form regarding the statements in the *Grief and Bereavement Assessment* you have just completed.

Please take the time to go through this and let me know your thoughts, such as what parts of the assessment form you thought were good or bad, and what questions you liked or disliked. I would also like to know whether I need to ask additional questions in order to assess your bereavement support needs.

This feedback form will take about 10 minutes to complete.

#### PART A:

1. How easy or difficult was it for you to complete the *assessment* form?

Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If not, which questions were not easy and why?

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2. Were the questions clear? ☐ Yes ☐ No

If not, which questions were not clear and how?

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3. Were the questions appropriate? ☐ Yes ☐ No

4. If not, which questions were not appropriate and how?

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5. Do you feel that the questions would adequately address your needs?

☐ Yes ☐ No

6. What questions should we have asked to meet your support needs?

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7. Approximately how much time did it take you to complete the assessment form?

--	--

minutes

8. How important do you think it is for a palliative care service to be concerned about your needs as a carer?

☐ Very important ☐ Somewhat important ☐ Not important at all

9. Any other comments?

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PART B: The following items are gathering information about you.

10. I am ☐ Male ☐ Female 11. Age \_\_\_\_\_

12. What is your relationship to the person you are caring for?

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13. Diagnosis of the person you are caring for.

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14. When was the diagnosis made (approximately)?

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15. How long has the person you are caring for, been under the care of a palliative care service?

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16. How many days has the person you are caring for been in this service, for this admission?

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17. Are you caring  
for others who also  
need your support?

---

18. What is the main  
language spoken in  
your home?

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19. What is your cultural background?

20. What is your highest level of education?

- ☐ No formal education
- ☐ Primary School
- ☐ High School
- ☐ Diploma/Certificate/T  
rade
- ☐ University

**Thank you for taking your time to  
complete this.**

**Your time is very much appreciated.**



## **Appendix H**

Semi-structured interview agenda for evaluation of health professionals at the consultative service.



### **Semi-structured interview agenda for evaluation: Consultancy service**

1. How do you think the carers found the assessment process, given carers have not been asked to engage in self-assessment by completing a form before?
2. Can you say something about how as an assessment model, this GABA measure suits the unit's routine and procedures?
3. If not, what do you see would be a better way to assess carer bereavement risk given assessment will be required by the standards?
4. If you do think this assessment model has utility, what would you see needing to change (if anything)?
5. Are you able to judge staff satisfaction/dissatisfaction using this GABA as an assessment model?
6. Could you say something about whether or not this GABA measure is making it easier to identify those carers who need follow-up following the patient's death?
7. If you think it is helping identify those carers who need follow-up, do you feel that your service is able to provide, (or refer the carers to) bereavement support services that match their need?
8. Have you got any other comments that you would like to add?



## **Appendix I**

Semi-structured interview agenda for evaluation of health  
professionals at the in-patient unit

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**Focus group of PC health professionals from the multidisciplinary team - inpatient unit.**

Clinical Nurse Manager:

Nurse (RN/CN):

Chaplain:

PC Physician:

Social Worker: Could not attend

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1. PICF signed & retained by participant. Photocopy of consent retained by researcher.
  2. Hand out a copy of the GABA to each participant.

**Interview Questions:**

Let's start with the tool.

1. How did you find it? (if they didn't use it....why not?)
2. What were the barriers to not using it?
3. Did you have any ideas of how the tool might have helped in practice in mind?
4. What would help for this to be incorporated into practice?
5. How could we make the shift needed to make this work in practice?
6. Are there any other comments you would like to add?